Independent living policies in the context of EU accession and membership: the case of Bulgaria

by

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‘I, Lilia Angelova-Mladenova, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.'

Abstract

The thesis explores the limits of disability policy reforms in Bulgaria in promoting disabled people's independence and inclusion, within the context of its accession and membership in the European Union (EU). It examines the interrelationships among: (1) EU influence, (2) policy frames and (3) the capacity and willingness of non-governmental organisations (NGOs) to advocate for independent living policies. Empirically, the research draws on documentary analysis and semi-structured interviews with domestic and European NGO, European Commission staff, and Bulgarian civil servants.

The research argues that Europeanisation did not challenge the highly problematic status quo of disability policy in Bulgaria, which is dominated by paternalism and segregation. What is more, this process actually facilitated the maintenance of the status quo. Using personal assistance policies as a case study, the research finds that while the EU influence supported the introduction of a social inclusion perspective, the strong focus on economic and market considerations, both prior and after accession, hindered the development of assistance services as a tool for independent living. Together with this, the changes in funding mechanisms, accompanying Bulgaria's membership in the EU, negatively affected NGOs capacity and willingness to advocate for policy change and shifted the balance of power towards the state and traditional, state-friendly, disability organisations. Although EU membership allowed NGOs to mobilise external pressure and influence domestic policy agenda (for example, in the case of deinstitutionalisation) the potential of actual policies to support disabled people's participation and independence remained limited.

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Impact Statement

Within academia, the research will contribute to the development of knowledge about the domestic impact of the European Union in the area of social policy, with a specific focus on disability policy – a field that Europeanisation literature has largely overlooked. It highlights the importance of adopting a broader perspective that encompasses the wider EU priorities and goals, the influence of which often remain obscured when the focus is narrowly placed on social policy alone.

The research adds to the emerging body of literature on ‘pathologies of Europeanisation’, which explores the EU’s unintended and undesired effects on domestic policies and institutions. By applying the concept of 'pathologies of Europeanization' to social policy developments, the study broadens its traditional focus beyond democratisation.

Selecting Bulgaria as a case study also fills an empirical gap . Previous Europeanisation research has focused on democratisation and rule of law, but the disability perspective allows for a more comprehensive understanding of Bulgaria’s domestic transformations in the context of EU accession and membership.

The research also contributes to disability studies by exploring how the EU influences domestic disability policies and actors. This perspective is new to disability studies and can lead to better understanding of the failures of domestic disability reforms.

Outside academia, the research will aid advocates at both the domestic and EU levels by improving their understanding of the EU's competing agendas within seemingly coherent policies. This insight will enable them to target and frame their policy demands more effectively. In addition, increased awareness of how domestic reform limitations are linked to EU policies and interventions will empower advocates to hold EU policymakers more accountable. Personally, I have been involved in EU-level and domestic disability advocacy since 2000. The findings from this research have influenced a number of papers and reports I have written or contributed to while working on the thesis. These include analyses of the challenges and opportunities presented by the European Structural and Investment Funds to support disabled people's inclusion, the domestic impact of the EU Disability Strategy 2010-2020, the realisation of disabled people's right to independent living, and the implementation of the UN Convention on the Rights of Persons with Disabilities in the EU.

The research will provide policy makers with a better understanding of the unintended and undesired effects of EU policies and interventions at the domestic level. This includes insights into both policy implications and the dynamics of power relations between domestic actors, including NGOs ability and willingness to initiate and support domestic reforms. Specifically, it will be of value to EU officials responsible for overseeing the European Structural and Investment Funds as a key post-accession instrument for influencing social policy. In addition, the research will increase the transparency of EU policies by uncovering the hidden agendas underpinning them. Lastly, it will contribute to better understanding of disability policies.

Abbreviations

CEE	Central and Eastern Europe
CRPD	Convention on the Rights of Persons with Disabilities
CRPD Committee	Committee on the Rights of Persons with Disabilities
DG Empl	Directorate General for Employment, Social Affairs and Inclusion
DG Just	Directorate General for Justice and Consumers
ESF	European Social Fund
ESIFs	European Structural and Investment Funds
EC	European Commission
EU	European Union
NCIPD	National Council for Integration of People with Disabilities
NGO	Non-governmental organisation
OMC	Open Method of Coordination

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Chapter 1: Introduction

In the last decades, the understanding of disability has undergone a profound transformation – from a largely medical one, focused on the individual impairment and recommending cure and therapy, to social, concerned with the barriers and the changes needed in the physical and social environment (Oliver 1986). Simultaneously, there has been a shift from viewing disabled people as passive objects of care to seeing them as agents capable of living independently, having choice and control in their everyday lives (European Network on Independent Living n.d.). These shifts were influenced by disabled people's social and political activism and the work of disability studies scholars, which both informed and was informed by this activism (Traustadóttir 2009). The social and independent living perspectives were incorporated into the United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2007. The Convention called on the states to develop a range of support options for persons with disabilities, including personal assistance, with a view to promoting disabled people's independence and participation in the community (Article 19). These perspectives were also endorsed by the EU. Its policies increasingly adopted a social and human rights understanding of disability (see Chapter 2). Beginning in the late 1980s, the EU policy turn culminated with the ratification of the CRPD, followed by the adoption of a framework strategy to support its implementation. of the, It emphasised participation in society through community support as a key action area.

Bulgaria also sought to align its policies and practices with the international and EU norms. At the end of 1989, marking the end of 45 years of state socialism, the main support for disabled people were large, warehouse-like residential institutions. These institutions, located in remote places, isolated disabled people from society, hindering their participation, and reproduced coercive and paternalistic practices. Thirty years later, the country's disability policies and legislation promote the inclusion and rights of disabled people, there is a range of support services in the community, including personal assistance, and hundreds of traditional institutions have been closed. The EU has been an important stimulus for these reforms through funding and political pressure (Mladenov and Petri 2020, Phillips 2012). However, despite appearing progressive the new support options failed to address the issues of exclusion and participation of disabled people and continued to reproduce segregation and paternalism. Contrary to public expectations, official rhetoric and NGO efforts, the EU accession and membership of Bulgaria did not significantly challenge the highly problematic status quo of disability policy.

This research explores the role of the EU in the lack of progress regarding independent living for disabled people in Bulgaria. Acknowledging that EU support and pressure have been important stimuli for reforms in Bulgaria's disability policies, the study asks whether and how they might have, unwittingly, contributed to the preservation of the status quo. It brings together multiple literatures: disability, public policy, and Europeanisation studies. This cross-disciplinary approach aims to provide a deeper, understanding of complex policy issues, beyond the limits of individual disciplines.

The perspectives of the social and medical models of disability, conceptualised by disability studies scholars (Oliver 1990), help reveal the disability-related assumptions underpinning policies and how these assumptions shape solutions. At the same time, the broader public policy perspective makes it possible to consider influences beyond disability. This is particularly important when discussing Bulgaria's EU accession and membership, which involved significant transformations in the economic, political, and social areas, and of which disability was only a small part. By engaging with discursive approaches to public policy (Durnova et al. 2016) the research explores the framing of disability policy in the context of broader EU priorities. It also looks at the implications of this framing on the proposed measures and their potential to support inclusion and independence.

The Europeanisation literature offers valuable insights about the potential and limits of EU influence on national policies and practices and the mechanisms of this influence. It shows that while Europeanisation pressures can lead to transformation of policies and practices (Anderson 2006, Guillén and Palier 2004, Jacoby et al. 2009), domestic changes made in response to these pressures can also remain only formal, ‘empty shells’ (Dimitrova 2010) if motivated exclusively by the desire to please the EU rather than to produce change. Most authors, however, discuss EU influence exclusively in positive terms, viewing Europeanisation as a force for good. In recent years, a different perspective has begun to emerge, looking at the ‘pathologies of Europeanisation’ (Börzel and Pamuk 2012). This refers to outcomes that differ from, or are even opposite, to the expected effects of EU influence. This still limited body of scholarship has focused mostly on democratisation and rule of law (Börzel and Pamuk 2012, Richter and Wunsch 2020, Mendelski 2016, Mungiu-Pippidi 2014). The present research feeds into these debates. It shifts the focus towards disability policy and explores how reforms in support services might have facilitated the preservation of the status quo.

Finally, this study also analyses the disability policy status quo by examining the willingness and ability of domestic NGOs to foster policy change in the context of EU accession and membership. NGOs were expected to be key drivers of change in the post-socialist transformation of Bulgaria, shaping decision-making and holding the state accountable (European Commission 1997a and 2000a). In addition, disabled people's activism has been crucial for challenging traditional segregating policies and promoting social and human rights perspectives (Jolly 2015, Morris 2010). Including NGOs in the analysis adds a new dimension to the discussion of Europeanisation of domestic policies and practices.

The research brings together domestic developments with the effects of EU accession and membership, recognising the important role of the domestic context and the limits of EU influence, especially in areas with a weak acquis. It explores the role of the EU in the lack of change by examining (1) ideas and policy frames, and (2) the capacity and willingness of NGOs to foster policy change. Using personal assistance policies as a case study, the research finds that while the EU's influence (through pressure, funding and models), supported the introduction of a social inclusion perspective, the strong focus on economic and market considerations, both prior and after accession, hindered the development of assistance services as a tool for independent living. Together with this, the changes in funding mechanisms, accompanying Bulgaria's membership in the EU, negatively affected NGOs capacity and willingness to advocate for policy change. This shifted the balance of power towards the state and state-friendly traditional disability organisations. While EU membership enabled NGOs to mobilise external pressure and influence domestic policy agenda (such as in deinstitutionalisation – see Chapter 5), the potential of policies to support disabled people's participation and independence remained limited. NGOs abilities for influence were restricted by the EU's explicitly expressed approval of these policies, which reinforced their legitimacy. Thus, Europeanisation not only failed to radically challenge the status quo, but facilitated its maintenance.

Bulgaria and disability policy as case studies

Bulgaria and independent living policy were chosen as case studies for several reasons. A key motivation was the author's comprehensive knowledge of and experience in the area – when I started writing, I already had over ten years of professional experience in Bulgaria's disability policy and a special interest in the country's development. This insider position and the knowledge of the context allowed me to gain an in-depth understanding of the issues analysed in the research.

In addition, despite the growing interest in Bulgaria (e.g., Surubaru and Nitoiu 2021), the country has been largely neglected by scholars exploring the interactions between EU enlargement and the transformations of domestic institutions and policies. While acknowledging that EU domestic influence differs across countries and policy areas (Grabbe 2003, Radaelli 2004, Goetz 2005, Bauer et al. 2007, Börzel 2002, Hughes et al. 2004), much of the research on candidates and new member states has focused on the Visegrád countries and the Western Balkans (Džankić et al. 2019, Wunsch 2018, Dąbrowski 2014, Sudbery 2010) with noticeably less attention given to the developments in the countries from the second accession wave – Bulgaria and Romania. Where the influence of the EU accession and membership on Bulgaria is discussed, it is often in areas, such as democratisation, judiciary, public administration, and fight against corruption (Noutcheva 2016, Noutcheva and Bechev 2008, Spendzharova and Vachudova 2012), i.e., areas of concern for the EU, which continued to be monitored years after the completion of the accession process (European

Commission 2012). The research addresses this empirical gap concerning Bulgaria, contributing to the understanding of its domestic transformations within the context of EU accession and membership.

In comparative terms, Bulgaria represents a case that is both typical and specific. Bulgaria, together with Romania, was considered a ‘laggard’ in the first wave of the EU’s eastern enlargement process (Noutcheva and Bechev 2008). Its transition to democracy and free market economy and the adoption of the EU acquis took longer than in the other CEE countries, leading to postponement of membership and continuation of EU monitoring and conditionality. In addition, Bulgaria has higher levels of corruption (Plaček et al. 2019, Todorakov 2010) and more extensive patronage (Kopecký and Spirova 2011) than other countries, which impacts on policymaking. There is also a wide-spread view that Bulgaria and Romania ‘remain deficient, “second class”’ EU members’ (Dimitrova 2021:295).

However, the broad pattern of development of the country’s disability policy is typical for the region. Most CEE countries have faced the same challenge of transforming the disability policies inherited from the state socialism, which were segregating and paternalistic, to align them with the ideas of inclusion and human rights promoted by the EU and the CRPD. Progress in this regard has been slow, with outcomes often reproducing old practices in a new form (Mansell et al. 2007, Mladenov and Petri 2020a and 2020b, Turnpenny et al. 2018). There are also similarities among CEE countries concerning the development of disability NGOs, with large membership-based organisations from the state-socialist period surviving the regime’s demise and remaining important players in the policy process (Fröhlich 2012, Mladenov 2018).

Disability policies and practices, and their development in the context of EU accession and membership, have also remained underexplored. The limited research on this topic mainly comes from disability studies (Waldschmidt 2009, Bećirević and Dowling 2014, Priestley 2012, Phillips 2012). The lack of attention from Europeanisation scholars can be explained with the discipline's strong focus on the formal adoption of EU rules and conditionality as a mechanism for inducing change. Typically, analysis of social policy developments in the context of EU accession and membership looks at the transposition and implementation of EU directives in the social area (Leiber 2005, Sissenich 2007, Falkner and Treib 2008), while EU disability policy mostly comprises of non-compulsory measures unsuitable for conditionality.

At the same time, the growing EU engagement with disabilities (see Chapter 2) and the shift in the understanding of disability from medical towards social and human rights perspectives, makes disability a useful lens for analysing domestic policy transformations and EU influence. Disability can also help understand the social and political dynamics in post-socialist countries (Rasell and Iarskaia-Smirnova 2014:2).

The EU accession and membership of CEE countries

The start of membership negotiations with the CEE countries attracted significant interests from researchers exploring the effects of EU enlargement on candidate and member states (Grabbe 2003, Goetz 2005, Hughes et al. 2004, Vachudova 2005, Epstein and Sedelmeier 2008). The EU's eastern enlargement was unparalleled in scale: accession negotiations were simultaneously conducted with ten CEE countries (and Cyprus and Malta), although accession itself happened in three consecutive waves[1]. In addition, countries in the region had unique political and socio-economic conditions compared to the older members and previous candidates. The pressure on these countries to transform their institutions and policies was also unprecedented, going beyond the *acquis communautaire* to areas in which EU institutions ‘have no legal competences vis-à-vis full member states (such as democracy and minority rights)’ (Sedelmeier 2011: 6). For the first time in the EU’s enlargement history, formal accession conditions were created, and candidate countries were required to make the necessary adjustments prior to accession, rather than afterwards, as was the case with the 1981 and 1986 enlargements when countries ‘were allowed into the EU with the aim of helping them to consolidate democracy after entry’ (Grabbe 1999: 20).

The legal framework for the accession process of CEE candidates was set in the so called ‘Europe Agreements’ – association agreements between the EU and third countries. These agreements provided the basis for economic, financial, social, and cultural cooperation and for the ‘gradual integration’ of the country into the Union. The formal accession conditions were established in 1993 by the Copenhagen European Council, which concluded that ‘[t]he associated countries of Central and Eastern Europe that so desire shall become members of the Union’ as soon as they fulfil a number of political, economic, and institutional requirements. The membership conditions involved ‘stability of institutions guaranteeing democracy, the rule of law, human rights and respect for and protection of minorities’ (political criteria), ‘existence of a functioning market economy’ (economic criteria) and ‘ability to take on the obligations of membership’, which referred to the adoption, implementation and enforcement of the *acquis communautaire*.

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[1] In 2004, eight CEE countries joined the EU: Hungary, Poland, the Czech Republic, Slovakia, Slovenia, Estonia, Latvia, and Lithuania. Bulgaria and Romania became members in 2017, and Croatia joined the Union in 2013.

The application of a country for membership, if not rejected by the European Council, was followed by an opinion (*avis*) from the European Commission (EC) on the readiness of the applicant to join the Union. It provided an assessment of the situation in the country in the light of the Copenhagen criteria and gave recommendations concerning the start of the accession negotiations. This assessment formed the basis for the Accession Partnerships, adopted by the Council of the European Union in 1998 and revised several times in the following years. They outlined, in a single framework, the priority areas for the development of each candidate, covering all the *acquis* as well as economic and political conditions. Candidates were required to prepare national programmes for adopting the *acquis,* including timetables for achieving the priorities set out in the Partnerships*.* The Commission monitored the progress of the candidates and published annual regular reports. The Accession Partnerships tightened EU conditionality by tying the financial assistance from the Union to the implementation of certain conditions, thereby giving the EU a ‘direct influence on policymaking in CEE, constraining it from the agenda-setting stage right through to monitoring of implementation and enforcement’ (Grabbe 1999: 9).

In its 1997 *avis,* the Commission recommended starting negotiations with only five of the CEE applicants – Czech Republic, Estonia, Hungary, Poland, Slovenia – and Cyprus. The other five CEE countries, including Bulgaria, and Malta were judged as not having met the economic conditions, and the start of the negotiations with them was postponed. This was ‘the first active application of conditionality on involvement in the accession process’ (Grabbe 1999: 13), which was explicitly based on the Copenhagen criteria.

Thus, in 1998, the accession negotiations were opened with the Czech Republic, Estonia, Hungary, Poland, Slovenia, and Cyprus, and in 2000 with Bulgaria, Latvia, Lithuania, Romania, the Slovak Republic and Malta. These negotiations focused on the terms – specifically, the pace of accession and reforms – under which candidates would adopt, implement, and enforce the *acquis.* For the purpose of accession negotiations, the *acquis communautaire* were divided into 31 chapters, reflecting the diverse policy fields in the EU legislation. Countries were required to adopt all existing community legislation before joining the Union. Negotiations could be concluded only when the EU was satisfied with the progress achieved by the countries in all policy areas. Negotiations with all applicants, except Bulgaria and Romania, were concluded in 2002, and the countries joined the EU in 2004. The chapters with Bulgaria and Romania were closed in 2004, paving the way for their accession in 2007.

However, for Bulgaria and Romania, EU conditionality in certain areas continued after accession. Due to insufficient progress in the areas of accountability and efficiency of the judicial system and law enforcement bodies, the fight against corruption and tackling organised crime, the Commission set out several benchmarks for the two countries to meet and established a Cooperation and Verification Mechanism for the first time as a measure for a member state (European Commission 2006a). It allowed the Commission to apply sanctions and safeguard measures if the countries fail to address the benchmarks adequately[2]. This was used in relation to Bulgaria in the beginning of 2008

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[2] The Accession Treaty with Bulgaria and Romania (2005) includes provisions that allow the EU to take protective measures against Bulgaria and Romania in the areas of the economy, internal market, and justice and home affairs (Protocol concerning the conditions and arrangements for admission of the republic of Bulgaria and Romania to the European Union. 2005, art. 36, 37 and 38). Such clauses were also introduced for previous candidates but were not used. Moreover, even the possibility for invoking them in the context of the 2004 enlargement 'was never seriously discussed' (Noutcheva 2006: 22).

to suspend the European funds (European Commission 2008). The Cooperation and Verification Mechanism for Bulgaria and Romania was closed as recently as 2023.

EU's influence on social policy

Europeanisation scholars explore the EU's influence on countries' domestic policies through a variety of mechanisms (Schimmelfennig and Sedelmeier 2005, Grabbe 2006, Börzel and Risse 2012)**.** Scholars who view Europeanisation as domestic change in response to EU rules and regulations (Featherstone and Radaelli 2003, Börzel and Risse 2006) emphasise the role of the EU as a driving force and explore the impact of EU conditionality as a key mechanism. From this perspective, adaptational pressures stem from countries' legal obligations and the incentive of EU membership drives compliance.

However, the relevance of conditionality differs across policy areas. It is less relevant in areas with a limited number of legally binding *acquis*, such as social policy, which provides minimal standards in labour law[3], health and safety at work[4], equal treatment[5], anti-discrimination[6], and health[7]. Pensions, social inclusion, employment, and social dialogue are also part of the social acquis; however, they are regulated mainly by 'soft' laws, which are not compulsory and therefore enforceable and sanctionable in case of non-compliance. The requirement for *compliance* with EU rules in these areas is

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[3] Covers requirement to inform and consult employees, conditions for part-time and for fixed-term workers, protection of employees in the event of insolvency of employer or transfer of undertakings, working time, etc.

[4] Includes directives on various aspects of health and safety at work, such as the minimum safety requirements for the use of work equipment, the use of personal protective equipment, etc.

[5] Focuses on equal treatment and payment for men and women, covering access to employment, vocational training and promotion, and working conditions, parental leave for childcare, safety of pregnant workers, etc.

[6] Addresses equality in employment and occupation and combating discrimination on the grounds of religion or belief, disability, age, sexual orientation, as well as race and ethnic origin.

[7] Centres on tobacco control and covers the manufacture, presentation and sale of tobacco products, tobacco advertising and sponsorships, and prevention of smoking.

substituted by *coordination* of states' policies around certain common objectives through the Open Method for Coordination[8] (OMC). This means that while the general priorities and targets in the area of social inclusion are agreed at EU level, the national governments are fully responsible for formulating and implementing policies.

Furthermore, the relevance of conditionality in the post-accession period is also limited. It played a key role during the CEE countries' accession, characterised by the introduction of formal accession conditions and the strong asymmetric relationships between the candidates and the EU[9] (Grabbe 2003). However, it became less important as a mechanism for influence after these states joined the EU and membership, the most powerful pre-accession incentive, could not be used to demand changes. After accession, hierarchical steering was replaced with horizontal mode of governance, making the period better suited for exploring alternative mechanisms[10] (Epstein and Sedelmeier 2008, Heinelt and Münch 2018).

Alternative to conditionality mechanisms consider the influence of ideas and norms and include both EU-driven forms of influence, such as diffusion through persuasion and socialisation (Börzel and Risse 2012), and state-driven forms, such as emulation through lesson-drawing (Jacoby 2004). This ideational perspective is better suited for studying the EU influence in the social area, which does not involve a mechanism for

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[8] The OMC is a voluntary process of policy coordination that relies on establishing common European goals, indicators, and benchmarks. These are then integrated into national policies through the development of national strategies and action plans, backed by periodic evaluations and peer review.

[9] The accession conditions increased the asymmetric power relations between the EU and the candidate countries. On the one hand, they give the EU greater power to demand compliance, compared to the previous enlargements. On the other, by setting detailed objectives in areas which were previously subject to inter-governmental bargaining they reduced the bargaining power of the candidate countries (Grabbe 2003).

[10] Despite the evolving dynamics post-accession studies largely remain focused on conditionality (Epstein and Sedelmeier 2008, Sedelmeier 2008, Levitz and Pop-Eleches 2010, Meyer-Sahling 2011). They aim 'to probe the extent and durability of pre-accession influences' (Epstein and Sedelmeier 2008: 802), exploring the (lack of) compliance in the absence of EU membership incentive.

coercion but relies on coordination and indirect tools for influence, like EU ‘soft’ law, the OMC, and the European Structural and Investment Funds (de la Porte and Pochet 2012:340).

Drawing on these alternative mechanisms for influence, numerous scholars have underlined the EU’s importance for social policy developments in both candidates and member states (Deacon et al. 2007, Lendvai 2004, Guillén and Palier 2004, Ferge and Juhász 2004, Sotiropoulos 2004). Cerami (2008:160) points out that the EU has been ‘undoubtedly a central force’ in the process of transformation of CEE social policy particularly though introducing new social policy ideas, interests and institutions. Similarly, Deacon et al. (2007) highlight the EU’s role in deconstructing traditional social policy domains and fostering new ones. According to them, the main EU contribution to the CEE countries’ social policy has been the generation of a discourse on social inclusion. As Lendvai (2004: 330) points out, social inclusion was a completely new concept for which some of the countries did not even have a word, ‘let alone meaningful understanding of it’. In their analysis of Hungarian social policy, Ferge and Juhasz (2004: 234) observe that ‘it has to a large extent been thanks to the Union (and the Open Method of Coordination) that poverty, social exclusion and inclusion have acceded not only to the European but also to the Hungarian political agenda’. The social inclusion perspective is particularly important in disability policy, where it serves as a key principle distinguishing between policies based on the medical and social models of disability.

In addition, the EU’s social dimension has been constantly expanding, opening up further opportunities for influence (Zeitlin and Vanhercke 2018, Ferge and Juhaz 2004).

Despite the uneven development of EU social policy (see Chapter 2), the EU's authority in the social area have expanded over the past two decades. For example, since 2001, the Council has the power to adopt measures that promote cooperation between member states in an increased number of social policy areas, such as social exclusion and social protection. In addition, member states have agreed to align their social policies with a set of common objectives and indicators defined at EU level through the Open Method of Coordination. Thus, social policy gradually entered the EU agenda despite the subsidiarity principle (Palier 2006).

Regarding the accession of the CEE countries, studies have shown that EU institutions paid limited attention to social policy (Ferge 2001). The European Economic and Social Committee (2000, quoted in European Trade Union Institute 2000:51) also noted out that the social dimension 'was hardly visible in the Europe Agreements' and that 'social convergence was not an objective in the same way as economic co-operation'. In addition, pre-accession funding for social policy was significantly more limited compared to other areas. For example, funding for social development and employment accounted for only 3.6% of the total Phare funding for the period 1990-1998 (de la Porte and Deacon 2002), whereas funding for the private sector, privatisation and restructuring, small and medium enterprises comprised 14.6% of the total budget, with infrastructure receiving 17.1%, and education, training and research 15.5% (European Commission 2000c). From the perspective of traditional conditionality, this may suggest that the EU's influence in this area was limited. However, such a conclusion overlooks the ideational influence, the unintended EU effects (pathologies), the effects stemming from the broader context and politics, such as the dominance of EU's economic agenda (see Chapters 2 and 4), and Europeanisation driven by domestic actors (Jacquot and Woll

2010). In addition, CEE countries' preparations to join the Open Method of Coordination and the European Structural and Investment Funds – key instruments for member states – started well before their membership, impacting the process. For example, in preparation for the OMC, countries were required to outline the challenges in the field of employment and social inclusion and the measures taken in the light of the EU's common objectives in these areas (see Chapter 4). Preparing for the EU Funds also required developing a national strategic reference framework, linking the National Reform Programme with Community priorities (Council of the European Union 2006).

The exclusive focus of early Europeanisation literature on conditionality has also been associated with a tendency to view the EU as a key driver of domestic change. While there has been a recognition of the importance of domestic factors, referred to as 'intervening variables' (Grabbe 2003) or 'facilitating factors' (Börzel and Risse 2003), the dominant strand of research explained the scope of domestic change with the size and credibility of the EU's positive and negative incentives, mainly related to financial and technical assistance and membership conditionality (Schimmelfennig and Sedelmeier 2005 and 2020). This perspective, however, has been unable to explain the varying impact of Europeanisation among countries and policy sectors (Börzel and Risse 2009) or why domestic policies change over time without major changes in structural features (Vanhala 2015). It has also been criticised for providing a one-dimensional view of domestic policymaking, which decouples policy outputs from domestic process and factors (Elbasani 2013) and for ignoring potential domestic drivers of change (Vanhala 2015).

With the 'domestic turn' in the Europeanisation literature, researchers have become increasingly interested in the way domestic factors interact with factors at EU level and mediate the EU's transformative power (Kakamias 2022, Dimitrova and Buzogáni 2014, Richter and Wunsch 2020). Scholars examining the unintended impact of the EU also emphasise the key role of the domestic context. Thus Mendelski (2015:319) notes that '[t]he EU's pathological power is an indirect effect, as its outcome depends on a country's domestic conditions'. Recent studies of social inclusion policies in CEE (Fylling et al. 2020) add to the debate by explaining the poor implementation of EU social inclusion policies with both flaws in the design of EU policies and the influence of various domestic factors, such as interests, power relations, and ideas. In the area of disability, the importance of the specific understanding of disability inherited from state socialism has been highlighted (Mladenov and Petri 2020a, Sandvin and Alexiu 2020). Finally, the domestic turn in the Europeanisation literature has also led to a growing interest in domestic factors as drivers of change (Spendzarova and Vachudova 2012, Buzogáni et al. 2022).

EU's influence on NGOs

NGOs appeared relatively late in the Europeanisation literature, due to the dominant top-down understanding of Europeanisation and the related to this focus on the institutionalisation of EU rules at the domestic level and the candidates' compliance with EU models. While this framework is suitable for studying the effects on public policy and the adoption of rules, it doesn't fully capture the influence of EU accession and membership on NGOs as this impact cannot be solely described in the terms of compliance and convergence (Salgado and Demidev 2018, Borragán 2004, Kutter and Trappmann 2010). With the accession of the CEE countries and the decreased importance of conditionality and rule transfer the interest in the impact of EU accession and membership on NGOs began to grow (Pleines 2005, Gąsior–Niemiec 2007, Gąsior-Niemiec and Gliński 2007, Parau and Bains 2008, Sudbery 2010, Carmin and Fagan 2010, Císař and Vráblíková, 2013, Salgado 2014, Wunsch 2018).

In terms of mechanisms or forms of influence, scholars explore the impact of: (1) EU funding and technical assistance for NGOs (2) the pressure on the government to involve non-state actors in the policymaking, and (3) the enlargement context and process. The first two mechanisms assume an active role for the EU, while the latter shifts the focus to NGOs as active agents and how they make use of the opportunities provided by the accession and membership. The scholarly discussions in each of these areas will be reviewed below.

In the early 1990s, the EU began to provide financial aid to NGOs in the region through various national and multi-country Phare[11] programmes, such as Democracy, LIEN (Link Inter-European NGOs), Partnership and Access (which substituted LIEN and Partnership programmes in 1999) programmes. These programmes were part of the EU's democracy promotion efforts which saw the development of an open civil society and the third sector as crucial for the establishment and functioning of democracy (OMAS Consortium 2001). In addition, NGOs had access to technical assistance in the form of training and consultation.

Assistance from the EU and other foreign donors[12] led to a dramatic increase in the

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[11] Poland and Hungary Assistance for the Restructuring of the Economy (PHARE) programme was initially created to assist the two countries in their democratisation. It was later expanded and became the main financial instrument supporting the preparations for accession of the CEE countries.

[12] A variety of multilateral and bilateral organisations, along with international NGOs provided financial assistance to the CEE countries. Examples include the United States Agency for International Development (USAID), the

number of NGOs in the CEE countries. For example, the number of NGOs increased 123 times in Slovakia and 81 times in Czech Republic between 1989 and 1999 (Nałęcz and Bartkowski 2006), and more than 90% of Polish NGOs were established after 1989 (Gąsior-Niemiec and Gliński 2007). The financial assistance also provided the ‘chronically underfunded’ NGOs (Börzel 2010:4) with the opportunity to continue and/or expand their work; to strengthen their infrastructure, and to develop skills and capacities in areas, such as management, fund-raising, and public relations (OMAS Consortium 2001). Due to very limited access to government funding, philanthropic giving or any other form of domestic funding, NGOs in the CEE countries[13] heavily relied on foreign donors, including EU funds, for their survival. In addition, providing funding directly to NGOs, rather than channelling it through the state, had a long-term positive impact by enabling NGOs to obtain know how and acquire the necessary management and implementation skills needed for the effective use of the EU Structural and Investment Funds (Raik 2003).

At the same time, although the number of NGOs in the CEE countries increased, Petrova and Tarrow (2007) note that there was a ‘high turnover’ of organisations established only to apply for funding or for tax advantages. The short-term nature and changing focus of EU funding (Carmin and Fagan 2010, Kutter and Trappmann 2010) increased NGOs’ dependency and made sustainability a challenge (Ishkanian 2003, Fagan 2006). These problems were aggravated by the absence of core funding in EU programmes – that is, funding covering basic organisational costs, such as office rent,

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Department for International Development (DFID), the United Nations Development Programme (UNDP), the World Bank, CARE, and Save the Children.

[13] However, there were significant disparities in financial viability among CEE countries. For example, at the end of the 1990s, Polish and Hungarian NGOs were in a significantly better situation compared to those in Bulgaria and Romania (USAID 2003).

equipment, personnel, and day-to-day work expenses – forcing organisations to frequently shift their focus (Stewart 2006).

Together with this, the excessive reliance on foreign funding detached NGOs from their grassroots constituencies (Börzel 2010, Raik 2006) leading to problems with legitimacy, trust, and representation. Moreover, by defining specific funding areas, foreign donors, including the EU, influences the types of projects and issues NGOs focused on. Thus, NGOs' agenda was shaped by the funders' priorities rather than by the local needs (Börzel 2010). What is more, NGOs were instrumentally used by the EU in pursuing its own social and political agenda, notably, in assisting with the implementation of the requirements of the *acquis*[14] (Rek 2010, Kutter and Trappman 2010). This eroded the autonomy of the NGOs as political actors since they 'lost the ability to determine their agendas independently' (Císař 2010: 739).

Some scholars have pointed out that EU assistance strengthened only organisations whose activities aligned with Brussels' priorities and those already established organisations with advanced skills and expertise (Kutter and Trappmann 2010, Fagan 2006, Rek 2010). The complex application process for EU funds effectively excluded grassroots and inexperienced organisations who lacked the capacity to develop project proposals, thereby channelling funding towards the same large NGOs (Fagan 2006). Krzeczunowicz (2004, quoted in Rek 2010:68-69) argues that this process had an even deeper impact on the development of the sector in the CEE countries, fostering 'a perception of inferiority of smaller CSOs', which were seen as not 'worthy of funding from the EU'.

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[14] Initially, Phare started as a 'demand-driven' programme. Over time, its priorities shifted, transforming it into an 'accession-driven' assistance (Bailey and De Propris 2004).

The complex application process for EU funding, among other factors, contributed to an increasing professionalisation of NGOs. This trend was further stimulated by the deliberate promotion of a specific organisational model – that of a professionalised advocacy NGO, which was the ‘organisational model that was recognised by donors as the legitimate manifestation of civic associations’ (Císař 2010: 739). Large amount of foreign funding was directed towards supporting NGOs to engage in policymaking, with the EU not being an exception. Towards the end of the 1990s, the EU began framing its support in terms of new modes of governance, viewing NGO involvement in policymaking ‘as a possible means to escape the ‘low-capacity trap’ of post-socialist accession states and to enhance implementation of EU rules’ (Kutter and Trapmann 2010: 43). However, to engage effectively in these new modes of governance, NGOs needed to possess the necessary capacities – ‘they need sufficient personnel, information, expertise, money, and organisational resources to make strategic decisions, to act as reliable negotiation partners and to offer state actors something in exchange for becoming involved in the policy process’ (Börzel and Buzogany 2008: 6).

After joining the EU, pre-accession funding programmes such as PHARE, were replaced by the EU Structural and Investment Funds and specific policy areas programmes (for example, LIFE+ was in the area of environment and PROGRESS – in the area of employment, social affairs and inclusion). However, the complexity of the application process remained a barrier for organisations lacking the required skills. Some new requirements, such as the applicant’s contribution of 20% to 80% of the project budget, also excluded less well-resourced organisations, now competing for EU funding on an equal footing with all European NGOs (Pleines and Bušková 2007). The lack of funding for capacity building has been another problem for the inexperienced organisations.

The EU also impacted NGOs indirectly – through the pressure it put on states to establish the necessary institutional framework for democracy, rule of law and human rights, to become more transparent and inclusive, to inform and consult NGOs, and to establish mechanisms for NGO participation in policymaking. This pressure has helped legitimise NGOs as partners in political decision-making ‘both on the part of the civil society organisations and to government officials’ (Rek 2010: 69). However, as noted earlier, a distinction should be made between formal compliance with EU norms and their practical implementation. In many areas EU rules have remained only ‘dead letters’ (Falkner and Treib 2008).

Other challenges to NGO involvement include limited cooperation with the state, often restricted to consultation (Börzel and Buzogany 2008: 2)’, which is a ‘tokenistic’ form of participation (Arnstein 1969); selective involvement of NGOs by governments ‘hand-picking’ loyal and trusted organisations, thus limiting the opportunities for other organisations to participate (Börzel and Buzogány 2008); and façade involvement in response to external pressure (Fagan and Wunsch 2018). It is also important to emphasis that participation in policymaking does not necessarily mean influencing the political agenda and decisions.

Finally, NGOs have been influenced not only by the actions of EU institutions but also by the enlargement context and process. Shifting the attention towards domestic actors, scholars have explored how NGOs make use of the opportunities provided by accession to empower themselves (Jacquot and Woll 2010, Salgado 2014, Sudbery 2010, Dimitrova and Buzogány 2014). For example, the enlargement has enabled NGOs to establish formal and informal contacts with organisations from other countries and transnational networks at the EU level, exchange ideas end experience, learn, benefit from contacts with decision-making, and strengthen their policy influence (Borragán 2004, Parau 2009, Rek 2010). Together with this, the new supranational level of governance has allowed NGOs to bypass the state with their claims and exert pressure from outside. NGOs have also been able to use the EU as a source of additional arguments and justification to legitimise their demands (Dimitrova and Buzogány 2014, Kutter and Trappmann 2010, Raik 2003). However, these opportunities have been mainly available to organisations whose values and goals fit with EU priorities, and those working in areas with 'thicker' *acquis* (Sudbery 2010). In addition, some of these mechanisms require significant efforts, time, and resources from NGOs (Salgado 2014), and their potential has weakened after accession when the EU's leverage over new members weakened (Sudbery 2010).

Research methodology

The research utilised several qualitative methods, including documents review, frame analysis of policy documents, and semi-structured interviews. The documents reviewed included statistical data, reports, memos from meetings, legal and policy documents, media publications, etc. When publicly available information was lacking or insufficient, official requests for access to information were submitted under the Law on Access to Public Information to the Ministry of Labour and Social Policy and the Registry Agency. Two requests were answered providing data to identify the trends in new NGO registrations per year (see Figure 2). A request concerning the composition of the working group for drafting the main EU-funded Operational Programme in the social area, the Human Resource Development Operational Programme, was declined (see Chapter 4, footnote 90). This rejection confirmed the research's findings regarding the lack of transparency in the design of the first programmes funded by the European Structural and Investment Funds (2007-2013).

Frame analysis was applied to policy documents setting out the framework and the rules of a key policy in the area of disability – assistance services (for more details about the rationale for this choice, see Chapter 4). Thirteen documents produced between 2002, when personal assistance service was first introduced in Bulgaria, and 2019, when it was institutionalised in a law, were reviewed. The frame analysis looked at how the introduction and development of assistance services was justified (what is the problem and why it was a problem) and the specifics of the proposed solutions. It also explored the normative assumptions underpinning the problem descriptions and the solutions. Domestic tendencies were then compared with developments at the EU level and potential mechanisms of influence were explored.

The interviews were conducted online and over the phone from December 2019 – toJanuary 2020, with an additional interview organised in 2021**.** A total of 13 semi-structured interviews were organised – 7 with domestic NGOs, 2 with an EU-level disability NGO, 3 with European Commission staff, and 1 with a domestic civil servant. The selection of NGO respondents sought to ensure that a diverse range of domestic organisations active in disability area are included. This encompassed nationally representative organisations of/for disabled people, organisations providing services, and human rights advocacy organisations. Another criterion that informed the selection of NGOs was their involvement in policy making. All interviewees were representatives of organisations that had sought to influence policymaking by participating in consultative bodies[15] or by engaging in lobbying and advocacy. The interviewed EC representatives included policy officers from Directorate General Regional Policy (DG Regio) and Directorate General for Employment, Social Affairs and Equal Opportunities (DG EMPL) familiar with the situation and developments in Bulgaria. The initial plan for interviews also included domestic policymakers, with up to 2 interviews planned. However, due to difficulties in finding respondents willing to take part, such interviews were not organised. To overcome this limitation, secondary sources of information, such as media interviews and conference presentations, were reviewed. These sources provided some insights into the policymakers' views. Additionally, an interview was conducted with a domestic civil servant, which provided useful information about policymakers' attitudes towards disabilities and NGOs.

Research design and outline of the chapters

The next chapter focuses on EU policies in the two main areas of the research – disability, located within the broader EU social policy context, and NGOs. It looks the evolution of the EU social and disability policies over time and explores the goals informing their development. The chapter raises several questions: What functions are EU social and disability policies expected to perform? What roles do EU policies and interventions prescribe to NGOs? In addition, the chapter looks at the development of EU disability policy from the perspective of key ideas and concepts in the area of disability, such as the social and medical model of disability, independent living, and human rights.

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[15] For example, the National Council for Integration of People with Disabilities or the consultative structures within the framework of the European Structural and Investment Funds (see Chapter 5).

Chapter 3 shifts the focus to the domestic level, providing a contextual background for the empirical analysis in subsequent chapters. It discusses Bulgarian disability policy and the understanding of disability from a historical perspective, showing the strong influence of medical model ideas and approaches form state-socialist era on present-day policies and practices in the area of disability. Together with this, the chapter explores the development of Bulgarian NGOs over the years, focusing on disability organisations and self-organisation of disabled people. It looks at the challenges and opportunities presented by the legal and political environment for NGOs' involvement in political activities and advocacy.

Chapters 4 and 5 offer an analysis of (1) disability policy frames and (2) NGOs ability and willingness to influence policies in the context of EU accession and membership. Chapter 4 identifies and explores the development of policy frames in a key support service for the independence and inclusion of disabled people– personal assistance. The analysis draws on policy documents produced between 2002, when the first assistance service was introduced, and 2019, when the research was completed. It aims to uncovers the various understandings of the problems, which assistance service aimed to address, and how they relate to EU-level discourses and policies. It also discusses the potential impact of these frames on disabled people's ability to have choice and control over their support.

Chapter 5 analyses NGOs' ability to influence policies, focusing on the final years of Bulgaria's EU accession and the membership, which are still underexplored in the Europeanisation literature. It looks at both the impact of EU funding and the promotion of NGO-state partnership, as well as how NGOs make use of the opportunities provided by the accession. The conclusions are based on a review of documents and semi-structured interviews with domestic and EU actors.

The final chapter summarises the main insights from the research, focusing on both framing and NGO policy influence, and their relevance for studies on the EU's domestic influence and disability studies. It links the empirical findings to the macro level discussions about EU social policy, its goals, and the legacy of state-socialism. The chapter emphasises the importance of the domestic context and the actors' agency in translating Europeanisation influences.

Chapter 2: European Union policy in the area of disabilities and non-governmental organisations

This chapter lays the ground for the analysis of Bulgaria's disability policy in the context of EU accession and membership. It explores EU policies in the two focus areas of the research: revealing the agendas behind EU's social and disability policies and its engagement with NGOs and discussing the understanding of disability that underpins EU disability policy.

The chapter begins by tracing the uneven development of EU social policy, a subfield of which is disability policy. It goes on to discuss some key concepts and perspectives in the disability area – the social and medical models, the independent living philosophy and the human rights turn. The development of EU disability policy is then reviewed through these main disability and social policy ideas. The chapter concludes with a focus on non-governmental organisations, exploring the EU's various strands of involvement of the EU with these organisations.

EU social policy development and underlying assumptions: relationship between economic and social aspects

The creation of EU social policy has not followed a linear trajectory – it is characterised by 'phases of great activity matched by lengthy phases of inertia' (Barnard 2012:5). Until the 1970s, EU social policy was limited and fragmented in its scope (Hartlapp 2019b). A brief period of increased EU intervention in social policy began in 1974 with the adoption of the First Social Action Programme. It was influenced by social unrest in

Western Europe at the end of the 1960s and the economic recession following the oil crises at the beginning of the 1970s, which led to a realisation that social measures are required to address the problems faced by the ‘losers’ of economic integration and to maintain social order. The Programme proposed measures to improve the living and working conditions of workers[16].

In the late 1970s and early 1980s, there was a period of stagnation in EU’s social policy, which mirrored the general stagnation in the EU policy. It was influenced by the opposition of the UK’s new prime minster, Margaret Thatcher, to the expansion of the EU’s social policy. The stagnation was followed by another spurt at the end of the 1980s and beginning of the 1990s, marked by the adoption of a Community Charter of Basic Social Rights for Workers. This period was driven by the growing awareness of the potential negative effects of the single European market on employees and the growing recognition that the social and economic dimensions are interrelated. The completion of the internal market was still viewed as the most effective way of creating employment and of ensuring well-being in the Community.

From the late 20th century, the EU’s commitment to developing a European social dimension began to grow. A key milestone in this process was the signing of the Treaty of Amsterdam in 1997, which gave the EU a broader competence in social policy and labour law. This treaty significantly expanded social provisions and introduced the fight against social exclusion, especially relevant for disabled people, as a key objective for the EU and its member states. The deepening of cooperation in the social area

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[16] This included directives in the areas of health and safety, transfer of undertakings, discrimination based on sex, and an action programme in the area of disability.

continued with the 2000 European Council in Lisbon, a ‘turning point’ in the evolution of the European social policy (Daly 2017: 98). It initiated a new policy process, the Open Method of Coordination, in various new social policy areas, including the fight against poverty and social exclusion, employment, education and training, pensions, healthcare and long-term care.

However, this expansion of social policy did not last. From the mid-2000s, there was limited attention to social policy issues in terms of strategies, resources and recommendations[17] (Copeland and Daly 2018). The social dimension returned with the ‘Europe 2020’ strategy – Europe’s development agenda for 2010-2020 (European Commission 2010a) – where social policy was explicitly included[18] and continued with the Social and Investment Package (2013) and the European Pillar of Social Rights (2017). They were responses to the demands for a more social Europe, following dissatisfaction with increasing EU inequalities after the financial crisis, and growing support for Eurosceptic parties (Hartlapp 2019b). Over the years, despite uneven development, EU’s social policy has undergone a significant transformation towards broadening its content and widening its instruments.

The priorities guiding the development of EU’s social policy have been set in various policy documents. Before 2000, EU’s social objectives were promoted through Social Action Programmes, which identified key areas for legislative and, more often, non-

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[17] Following the accession of the CEE countries, the political context in member states shifted towards the right of the political spectrum (de la Porte 2019; Hartlapp 2019b) prompting an enhanced focus on competitiveness and structural reforms, and flexibility. This shift is reflected in the revised Lisbon Agenda (European Commission 2005a) from which the social element was almost completely removed, while a stronger emphasis was placed on growth and jobs. The financial crises then led to an increased focus on austerity and strengthening of economic governance, prioritising budgetary and fiscal discipline (Copeland and Daly 2015).

[18] For example, one of the targets is related to fighting poverty and social exclusion.

legislative initiatives. Three such programmes were implemented – in 1974 (running until the early 1980s), 1989 (linked to the Charter on Fundamental Rights and running until the early 1990s) and 1995-1997. During the Lisbon process (2000-2010), the framework for the development of EU's social policy was set by the EU's Social Policy Agendas – 2000-2005, 2005-2010 and the 2008 renewed social agenda. In the 'Europe 2020' strategy, different flagship initiatives were proposed to help achieve EU's social priorities, with the 'European Platform against Poverty and Social Exclusion' being particularly relevant. The main financial instrument supporting the implementation of EU's social policies has been the European Social Fund (ESF)[19].

Essential for understanding the nature of EU social policy is the relationship between economic and social aspects. The European Union began as an economic project and EU integration has historically been primarily a process of economic integration and building of a common market. This focus has had two major implications for EU social policy development. First, there has been a 'fundamental asymmetry between policies promoting market efficiencies and those promoting social protection and equality' (Scharpf 2002:665), with greater importance attributed to the former. This is evident in the increasingly different approaches applied to economic and social issues – harmonisation and legally binding regulation in economic area and coordination and non-compulsory policies in the social – resulting in advanced market integration and limited welfare state integration.

Second, EU's social policy has been largely subordinated to economic policy, serving

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[19] Other EU funds are also relevant, such as the European Regional Development Fund, the European Agricultural Fund for Rural Development and the EU Programme for Social Change and Innovation. The latter introduced in 2014, replaced the PROGRESS programme the main community programme, funding measures in the area of employment, anti-discrimination, gender equality and the fight against social exclusion.

as its ‘handmaiden’, thus ‘harnessing a social idea to an economic cause’ (Daly 2008:16). Instead of serving social goals in their own right, such as social justice, equality and solidarity, EU’s social policy has become instrumental to economic policies (Lendvai 2005).Following the developments in EU social policy in the 1980s and early 1990s, Streeck (1995) argued that EU’s social policy was primarily concerned with ‘market-making’ rather than ‘market-correcting’; that is, orientated towards creating an integrated labour market and enabling it to function efficiently, for example, through regulations removing barriers to free movement of labour and supporting competition (negative integration), rather than seeking to correct the outcomes of its functioning (positive integration).

After the initial period of market-building, which left little room for market-correcting social policy, the development of EU social policy at the turn of the 21st century, when the EU accession of Bulgaria was underway, continued to reproduce the subordination of the social to economic goals. At that time, the EU’s vision of social policy became increasingly productivist – a general trend in the development of welfare states in Europe (Taylor-Gooby 2008) – viewing social policy as a prerequisite for economic development and efficiency in the new knowledge-based economy, thus providing an economic rationale for social policy provision. The Lisbon Agenda, for example, sought to ‘strength the role of social policy as a productive factor’ (European Commission 2000b:5) and called for ‘modernising and improving’ social policy, understood as transition from policies correcting market inefficiencies towards policies promoting market efficiencies (European Commission 2003a:26). The Social Investment Package (European Commission 2013a) continued this tendency, promoting measures orientated towards the future and aiming to ‘prepare’ people to face social and economic challenges rather than ‘to repair’ consequences retrospectively (market-correcting). It sought to develop human capital – for example, though programmes enhancing skills and capacity, and to ensure the efficient use of this capital – for example, through active labour market policies and improved childcare provision (European Council 2000c). The function of social protection was instrumentalised in the service of the economy – during ‘adverse periods’ to allow ‘previous investments made in human capital to be preserved’ (European Commission 2013a:3).

The decline of EU social policy in the mid-2000s – beginning of 2010s was accompanied and reinforced by a shift in the EU’s view of social spending as costs rather than investment, and a burden rather than as a resource for the economy, in the context of the 2007 financial crisis. Social policy objectives became subordinated to reducing public deficit, which rendered ‘their achievement de facto nearly impossible’ (Crespy and Menz 2015:762). Framing the financial crisis mainly as a problem of public spending, the Commission called for massive cuts in welfare budgets to reduce government deficits. It strongly encouraged, even demanded from some member states, fiscal austerity. Several legislative acts[20] were adopted in 2011, introducing a new microeconomic surveillance tool and providing for sanctions if a member state’s deficit exceeded a certain percentage of GDP. Together with this, the EC further emphasised the importance of shifting from ‘passive’ measures, such as income protection (unemployment assistance), to ‘active’ measures, which make protection conditional on training or job search and are ‘designed to reward return to work for the unemployed and some inactive people through time-limited support’ (Council of the

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[20] In 2011, the so-called ‘six pack’ representing a collection of new laws aimed to reform the Stability and Growth Pact and thus strengthen the EU’s fiscal and economic governance.

European Union 2011:23). Benefits were increasingly presented as obstacles and the EC encouraged member states to address ‘benefit dependency’ and ‘benefits traps’ and introduce stronger benefit conditionality. The language of ‘traps’ and ‘welfare dependency’ reveals some of the underlying economic concerns of the Union related to reducing benefits spending and withdrawing support, particularly relevant for disabled people (O’Brien 2014).

Overall, in the last decades, despite an increased emphasis on social issues (Zeitlin and Vanhercke 2018, Bekker 2015), there has been a tendency towards strengthening the market-supporting dimension of EU social policy, accompanied by a ‘massive decline’ in the social policy in its own right (Hartlapp 2019a: 78).While social policy has remained part of the political agenda, it has focused on integration through markets and de-regulation, rather than re-regulation (Crespy and Menz 2015:754). Social objectives have been subordinated to higher-order economic objectives aiming to support market functioning, promote competition and encourage labour market participation and flexibilisation (Copeland and Daly 2015 and 2018).

A central place in the EU’s social policy approach is given to employment. Indeed, the focus on rebuilding the welfare state around work [in EU’s jargon –- modernising social protection] through social investments ‘has become iconic in the European context’ (Deeming and Smyth 2015:299). Increased employment is seen as key to achieving the Union’s economic goals related to competitiveness and growth. At the same time, it is promoted as ‘the best protection against social exclusion’ (European Council 2000a: para.23). Understanding exclusion mostly as persistent poverty (Daly 2006), the EU encourages states to put in place policies seeking to increase the participation of disadvantaged groups in employment: ‘More and better jobs are the key to social inclusion’ (European Council 2000a: para 10). Despite broadening the social area, the focus of social policies has remained on employment[21].

The European Union stresses on the ‘dual’ social and economic objectives of its social policy – as a productive factor and an instrument for achieving greater social cohesion. However, it is questionable to what extent goals related to social inclusion and social cohesion are social goals in their own right or are mostly legitimised by their potential to contribute to economic development. As Daly (2006:5) observes, ‘under the EU Treaties, the social is a contingent space in the EU – activities to promote social cohesion can be justified only if undertaken in the service of promoting economic cohesion’. Thus, a key argument for the Union’s focus on social cohesion and social inclusion is their contribution to achieving the Union’s economic goals. ’It is a precondition for better economic performance that we create a society with greater social cohesion and less exclusion’ (European Council 2000b).

Conceptions of disability

EU disability policy, as a sub-sector of social policy, has been strongly influenced by the interplay between economic and social, as discussed above. At the same time, it has been shaped by developments in the disability area notably, the shift from an individual to a social understanding of disability and the human rights perspective. This shift involves different assumptions about the causes of problems faced by disabled people, demanding different policy solutions. This section will discuss the different conceptions

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[21] See also Carmel (2005). In her analysis of the Open Method for Coordination on social inclusion, she observes that while some attention is given to policies addressing housing and health care needs, there are no specific indicators for housing, and those for health are very limited. She concludes that the indicators ‘demonstrate a concern with employment which tends to enhance the economic agendas evident in the EU’ (Carmel 2005: 49).

of disability and their impact on policymaking and the self-organisation of disabled people, before going on to examine (in section 2.3.) how different understandings of disabilities and the tension between economic and social are reflected in EU's disability policy.

Individual (medical) and social models of disability

The traditional understanding of disability in Western Europe during much of the 20th century, was individualised and medicalised. This perspective views disability as an attribute of the individual, as a 'personal tragedy'. It attributes the difficulties experienced by many disabled people in education, employment and societal participation to their physical or psychological limitations, resulting from traumatic events, such as accidents or diseases (Oliver 1986). For example, the International Classification of Impairments Disabilities and Handicaps (WHO 1980:28) defines disability as '[a]ny restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'.

At the beginning of the 1980s in the UK, a new, radical redefinition of disability emerged, known as the 'social model of disability' (Oliver 1990). Drawing on disabled people's own understanding of the reasons for their exclusion from society (*cf.* UPIAS, 1976), the social model breaks the causal link between impairment (the medical aspect) and disability (the social aspect). It shifts the focus from the individual to the societal barriers – environmental, economic, and cultural that restrict disabled people's participation in economic and social activities. As Morris (1993: x) notes:

> an inability to walk is an impairment, whereas an inability to enter a building because the entrance is up a flight of steps is a disability. An inability to speak is an impairment but an inability to communicate

> because appropriate technical aids are not made available is a disability. An inability to move one's body is an impairment but an inability to get out of bed because appropriate physical help is not available is a disability.

The traditional view assumes that since the disadvantaged situation of disabled people is caused by individual impairment, and this impairment cannot be cured, the disadvantaged situation cannot be changed. From a social model perspective, the disadvantaged situation is caused by the socially constructed environment, which can be changed, thus eliminating disability. Achieving this requires the collective organisation of disabled people for social change (UPIAS, 1976).

The table below summarises some of the main differences between the social and medical models, drawing on Oliver (1996)

Table 1: Individual and social models

Individual model	**Social model**
Disability is individual problem (deficit)	Disability is social problem (barriers)
Disability is caused by impairment	Disability is caused by society
Dominance of experts	Individual and collective responsibility
Expertise	Experience
Disability as a 'personal tragedy'	Disability as social oppression
Care	Rights
Individual change	Social change
Isolation	Participation
Medical solutions, institutionalisation	Community services
Policy	Politics

The independent living philosophy

The independent living philosophy also challenges the traditional view of disability. Developed in parallel with the social model of disability, independent living originates from disabled people's movement for human rights (Jolly 2015).

Independent living emphasises choice and control and argues that ‘disabled people should have the same opportunities for choice and control as non-disabled people’ and that ‘any assistance required should be controlled by disabled individuals themselves’ (Morris 2004). This understanding challenges the traditional notion of independence as the ability to be self-sufficient and able to cope without external support. In the words of Adolf Ratzka (1997: n.p.), one of the pioneers of the Independent Living Movement in Europe:

> Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own.

The social model and the independent living philosophy are closely linked and complementary. The social model ‘underpins the aims of the independent living movement’ (Jolly 2015:463), while at the same time, ‘the idea of independent living enriches the social model’ (Mladenov 2021:14) by emphasising that removing environmental and social barriers to participation should be accompanied by enabling choice and control.

Policymaking and self-organisation of disabled people

The traditional understanding of disability, often termed ‘individual’ or ‘medical’ model[22], gives rise to policies centred on medical interventions and rehabilitation and aiming to ‘fix’ the disabled individual and to restore their ‘normality’ (Oliver and Barnes 1998). Its implicit assumption, that all individuals can be changed and adapted, while the environment – not (Oliver and Barnes 2012), leads to the proliferation of institutional solutions, such as residential institutions, special schools, and sheltered employment., Thes institutions are created to accommodate people whose disability cannot be corrected and who cannot fit the educational system, the labour market or society in general. They segregate disabled people from the society. The responsible Ministries are usually the ‘caring’ Health and Welfare (Quinn 1999: 286).

Since disabled people are seen as incapable of making decisions for themselves, (medical) experts have the power to decide where they ‘should live, whether they should work or not, what kind of school they should go to, what kinds of benefits and services they should receive and in the case of unborn disabled children, whether they should live or not’ (Oliver 1996: 36). Disability policies are also developed in the absence of disabled people and are influenced instead by experts and organisations *for* disabled people claiming to represent or speak to them. The individual perspective on disability impedes self-organisation of disabled people because it suggests that individual problems call for individual solutions.

Policies based on the social model and independent living aim to remove the existing barriers in society rather than to correct the individual. Priority is given to measures,

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[22] In the literature this model is usually referred to as ‘medical model’ due to its emphasis on medical solutions. The term ‘individual model’, however, is preferred by Oliver. In this text the two terms will be used interchangeably.

such as accessibility, person-led personal assistance services, technical aids, and training of teachers to work with disabled children. This does not mean that individual-based or medical interventions have no place, just the opposite. The problem comes when doctors try to cure disability rather than illness (Oliver 1996).

The social model 'refuses to view the specific problems faced by disabled people in isolation from the 'totality of disabling environments' (Oliver 2004). This means that addressing the problems of disabled people requires coordinated implementation of measures across different policy areas. For example, addressing unemployment among disabled people involves more than labour market interventions, it also requires ensuring transportation, physical environment and educational systems are accessible to all and that there is variety of support services in the community, including personal assistance. Only the availability of a range of support options cand allow disabled people to have the same control over their lives as others.

The social model explicitly encourages the self-organisation of disabled people for social change:

> It is society that has to change not individuals and this change will come about as part of a process of political empowerment of disabled people as a group and not through social policies and programmes delivered by establishment politicians and policy makers nor through individualised treatments and interventions provided by the medical and para-medical professions. (Oliver 1996: 37)

It questions the legitimacy of organisations claiming the expertise in solving disabled people's problems by arguing that the nature of these problems requires political, not expert, actions.

Significance and critiques of the social model and the independent living philosophy

The social model and the independent living philosophy have had a crucial impact on disabled people and the disability movement. They have empowered disabled people to organise by replacing the traditional understanding of disability, which attributed their disadvantaged situation to personal deficits, with a perspective which views it as arising from the social oppression. It made possible the identification of a clear political strategy around which to organise – the removal of barriers in society (Shakespeare and Watson 2001). Therefore, the social model 'should be acknowledged and celebrated as a powerful tool for political struggle' (Thomas, 2014:14).

These perspectives also have important implications for policymaking. For example, the International Classification of Functioning, Disability and Health the World Health Organisation (2002), acknowledges the social model and adopts a 'biopsychosocial' approach, seeking to integrate social and medical models. The distinction between these models also played 'a pivotal role' during the negotiations of the United Nations Convention on the Rights of Persons with Disabilities (Degener 2016a:2). The Convention endorses the social model recognising that '… disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'[23].

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[23] For a discussion on the influence of the social model on the United Nation's instruments, see also Stein (2007).

However, the social model and independent living philosophy are not without critiques. For example, many disability studies scholars question the social model's denial of personal experiences related to impairment, such as pain, fatigue, or depression, and emphasise the need to include the psycho-emotional dimensions of disability, which can also be disabling (Morris 1993, Reeve 2004). In addition, the exclusion of impairment overlooks the fact that disabled people's physical differences also impose restrictions on their activities, which cannot be overcome solely by measures based on the social model's principles (French 1993). In response to these criticisms, Oliver (1996:38) highlights the political nature of the social model as 'a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or other professional treatment'.

Disability and human rights

In the last couple of decades, disability issues have been strongly linked to human rights. The move towards disability rights was first institutionalised internationally with the adoption of the United Nations Standard Rules on the Equalisation of Opportunities of Persons with Disabilities in 1993. They were an outcome of the Decade of Disabled People (1983-1992), which sought to promote measures supporting the realisation of the goals of 'full participation' of disabled people and 'equality' (United Nations 1982).

The disability rights discourse was further developed in the UN Convention on the Rights of Persons with Disabilities, drafted with the active involvement of disability rights organisations (Moriarity and Dew 2011). The Convention, together with its Optional Protocol, was adopted by the General Assembly of the United Nations in December

2006, following a short period of negotiations[24] and entered into force on 3 May 2008, and as of November 2019, was ratified by 180 countries, including the European Union. Its adoption was praised by disability scholars as a major step towards equality of disabled people (Arnardóttir and Quinn 2009, Oliver and Barnes 2012). While the Convention did not create new rights, it provided 'a disability-sensitive articulation' of existing rights and raised the awareness of the disability dimension of human rights. It also brought attention to independent living and participation in society as human rights issues (Lawson 2009).

The CRPD incorporates both the social model of disability and the independent living philosophy. It endorses the social model of disability and 'takes it forward by explicitly recognising disability as a human rights issue' (UN Office of the High Commissioner for Human Rights 2010:8). This involves a shift from viewing disabled people as 'objects' to be cared for through social protection, health and charity programmes towards viewing them as citizens, as 'subjects' with rights, capable of claiming those rights and becoming active members of society (UN High Commissioner for Human Rights 2006). Individualised support services thus become a right rather than a form of medical, social or charity care (CRPD Committee 2017). Together with this, the CRPD promotes independent living. Thus, Article 19 – Living independently and being included in the community – requires states to ensure that disabled people have access to a range of in-home, residential and other support services that support inclusion and prevent isolation and segregation. At the same time, it emphasises that all measures in the area of disability should ensure respect for the independence, dignity and autonomy of

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[24] According to the UN website (https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html), the Convention was the fastest negotiated human rights treaty, with 8 sessions of the Ad Hoc Committee of the General Assembly held during the period 2002-2006.

disabled people, including their right to make own choices (Article 3 – General principles). It thus replaces paternalism with autonomy, and the focus on needs and charity – with rights (‘Rights not charity’ is one of the main slogans of disabled people’s movement).

Another important contribution of the CRPD is that it combines two sets of rights – civil and political (‘negative’ rights), and economic, social and cultural (‘positive’ rights)[25] (Arnardóttir and Quinn 2009). The rights-based perspective typically views disability as a product of inequality and discrimination (Degener 2016b). Traditionally, equality is understood in the context of civil rights, and viewed as a ‘negative duty, restraining the State or private individuals from discriminating against individuals’ (Fredman 2006:2). The presence of ant-discrimination legislation is thus essential for challenging discriminatory practices against disabled people, such as forced treatment, forced abortion, confinement, or denial of access to healthcare (CRPD Committee 2018). However, the inclusion of disabled people cannot be achieved without positive measures by the states, such as accessible transportation and individualised support services. As Quinn (2009:92) notes ‘[t]here is a limit to what the non-discrimination tool can achieve in the disability context’, it ‘cannot do the full job of economic, social and cultural rights’. Therefore, by going beyond anti-discrimination and combining these two sets of rights, the Convention has the potential to contribute to the real inclusion of disabled people in society.

The adoption of the Convention has been of utmost importance for disabled people

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[25] The ‘negative rights’ include provisions such as freedom from torture or cruel, inhumane, or degrading treatment or punishment (Article 15), freedom from exploitation, violence and abuse (Article 16), liberty of movement (Article 18), among others. ‘Positive rights’ include access to education (Article 24), health (Article 26), work and employment (Article 27), independent living (Article 19), etc.

around the world, providing an additional source of legitimation for their calls for legal and policy changes. Not only are disabled people able to use the CRPD to pressure domestic policymakers directly, but they can also influence them indirectly, through the Committee on the Rights of Persons with Disabilities (CRPD Committee). This is a body of independent experts, which monitors the implementation of the CRPD by examining states' regular reports[26] and issuing recommendations. It also provides authoritative interpretations (General Comments) of the CRPD's provisions. When reviewing the state reports and drafting general comments, the CRPD Committee takes into account the views of non-state actors.

The ratification of the CRPD also created opportunities for disabled people, NGOs and other interested actors working in EU member states to use the Convention to influence EU policies and through them – domestic policies and practices. Many European networks and organisations have submitted contributions to the CRPD Committee, commenting on the implementation of the CRPD in the EU and seeking to influence the Committee's conclusions and recommendations to the EU.

There are, however, important challenges when it comes to the potential of the right-based approaches to bring about a real change in the situation of disabled people. For example, Oliver and Barnes (2006: n.p.) note that if pursued as an end in itself, a right-based approach to disability can be counterproductive because '[h]aving legal rights does not mean they will be enforced and even if they are, that enforcement will achieve the desired aims'. Along these lines Mladenov (2013:75) notes that 'the CRPD can only

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[26] Each State Party to the Convention must submit a comprehensive report on the measures taken to implement its obligations under the Convention within two years of its entry into force. Subsequent reports are required every four years, as stipulated in Article 35).

invite certain responses and open up possibilities for the deployment of certain meanings and practices, but it cannot determine these responses, meanings and practices’. Thus, ‘community services’ can be understood to mean independent living type of support with choice and control or more traditional, institutional type of care, such as small group homes. Revealing and challenging the assumptions underpinning certain policies could thus be a useful strategy for disabled people and their organisations seeking to influence policy measures.

EU disability policy

Similar to social policy, the development of EU disability policy, , began relatively late. The founding Treaties of the EU did not contain any reference to disability, and the Union had no specific competences in this area until as late as 1998. The EU’s soft instruments also did not address disability issues until the 1970s. This absence can be explained on the one hand, with the European Union’s exclusive focus on economic integration and economic goals, which put disability, and social issues in general, outside of the Community’s agenda. On the other hand, at that time the dominant understanding of disability was framed by the medical model, which meant that the exclusion of disabled people was seen as ‘natural’ rather than ‘driven by implicit social choices’ (Quinn 2005:300). In other words, disabled people were seen as being incapable of working and contributing to the economy due to their physical or intellectual deficits.

From medical to social understanding and human rights perspective

The first spurt for the development of disability policy came with the 1974 Social Action Programme which recommended the establishment of an action programme for ‘handicapped workers in open market economy’ as one of the priorities in the social area. Later that year, the Council established the Initial Community Action Programme for the Vocational Rehabilitation of Handicapped Persons, covering the period from 1974 to 1979. Over the next 20 years EU disability policy primarily took the form of action programmes centred on networking and information exchange. After a short break, which reflected the general stagnation in the social policy area at the beginning of the 1980s, the First Community Action Programme on the Social Integration of Handicapped People was established, covering the period 1983 – 1988 (Council of the European Communities 1981). It was followed by HELIOS I[27] Community Action Programme for Disabled People, 1988 – 1991 (Council of the European Communities 1988), and HELIOS II Community Action Programme to Assist Disabled People, 1993 – 1996 (Council of the European Communities 1993). Additionally, in 1989 the European Social Fund was reformed, and its role in funding disability related programmes, through the HORIZON programme, was enhanced. Overall, this abundance of action programmes and the almost total lack of other initiatives are telling about the limited legal competences of the Community in the area of disability.

A review of these action programmes reveals how the EU’s understanding of disability has evolved, moving from an exclusively medical approach to one based on social and human rights. The first two programmes were firmly within the framework of the individual model of disability. They saw disabled people’s participation in employment as rehabilitation and promoted the establishment and development of networks of rehabilitation and training bodies at EU level, rather than of organisations representing

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[27] HELIOS is an acronym for Handicapped People in the European Community Living Independently in an Open Society.

disabled people. The Initial Programme also referred to disabled people as 'handicapped', defining 'handicap' as 'any limitation of a person's physical or mental ability which affects their daily activity and work'. While its successor showed first signs of an emerging social discourse on disability, indicated by the use of the terms 'disabled people'/'people with disabilities' and the acknowledgement of the importance of social integration, the proposed activities show that apart from the rhetoric little has changed.

HELIOS I (standing for Handicapped People in the European community Living Independently in an Open Society) continued the shift away from the medicalisation of disabilities by including measures aimed to support independent living (for example, related to mobility and transportation, access to public buildings and facilities and housing) and distinguishing between impairment and disability, although it failed to recognise the role of environmental barriers in the definition of disability and kept the focus on experts. HELIOS II (1993-1996), on the other hand, showed a significant evolution in the Commission's approach to disabilities (Mabbett 2005) as the language of rights and opportunities could be seen in the formulation of the principal objective of the programme, namely 'to promote equal opportunities for and the integration of disabled people' (Art. 1). Another innovation was the emphasis on the active involvement of disabled people in policymaking[28], which led to the establishment of the European Disability Forum (EDF), consisting of 24 organisations of disabled people from all member states, as a consultative body to the European Commission on the Programme. After the end of the Programme, EDF continued its existence as an independent body with funding from the EC to become the largest European platform of

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[28] Consultations with disabled people took place and during in Helios I, but they were limited in scope.

disabled people[29] actively engaged in advocacy and awareness raising. Thus, arguably the most important long-term result of these action programmes was their contribution to improving dialogue and building solidarity between disability NGOs, empowering them to engage more actively in discussions about disability policies mainly at EU but also at national level (European Commission 1998). As Quinn (1999:304) argues, HELIOS II ‘was a catalyst to the awakening of the European NGO community to the significance of the EU Treaty law’.

The EU’s turn to social and rights-based approach to disabilities continued with the adoption of the first comprehensive European Disability Strategy in 1996. Inspired by the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, it marked a paradigm shift in EU policies towards a rights-based approach and away from traditional ideas focusing on social and economic compensation. The Strategy acknowledged the role that organisation of society has for excluding disabled people, explicitly criticised the approach based on charity and special provision and promoted an ‘equality of opportunity approach to disability’. It also stressed on the need to mainstream disability, as opposed to having a parallel to the mainstream track for disabled people, as a tool to achieve real participation of disabled people in society. The idea of mainstreaming implies ‘that education in ordinary schools should be preferred to separate special education, that institutionalisation should be avoided whenever possible, and that facilitating employment in the open labour market is preferable to employment in sheltered workshops’ (Mabbett 2005:108). The Strategy, however, did not propose further legislation in the area of disability but stressed on the exchange of

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[29] As of 2024, EDF claims to represent 100 million Europeans with disabilities. For more details, visit https://www.edf-feph.org/about-us/about-us-2/.

information, statistics and experience.

The 1996 Strategy was carried forward by the European Disability Action Plan, the adoption of which was influenced by the 2003 European Year of People with Disabilities. It aimed ‘to boost equal opportunities for people with disabilities’ and explicitly acknowledged the EU’s turn to the social model of disability:

> The EU also sees disability as a social construct. The EU social model of disability stresses the environmental barriers in society which prevent the full participation of people with disabilities in society’ (European Commission 2003b: 4).

At the end of 2010, the EC adopted a new strategic framework in the disability area – the European Disability Strategy 2010-2020 – which sought to provide ‘a comprehensive multiannual framework for implementing the United Nations Convention on the Rights of Persons with Disabilities[30] at EU level’ (European Parliament 2017). The Strategy fully endorsed a social model and rights-based approach to disability, focusing on eliminating barriers and aiming to ‘empower people with disabilities so that they can enjoy their full rights and benefit fully from participating in society and in the European economy’ (European Commission 2010b). It identified eight main areas for action – accessibility, participation, equality, employment, education and training, social protection, health, and external action – drawing on the UN CRPD. This strategy was followed by the Union of Equality: Strategy for the Rights of Persons with Disabilities

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[30] The Convention was concluded by the EU in the same year, becoming legally binding for the EU and the Member States.

2021 – 2030 (European Commission 2021a), which put a strong emphasis on independent living, seen as ‘a cornerstone’ in the EU’s equality agenda (Helena Dalli, cited in EEG 2019). The Commission sought to promote independent living and inclusion more actively, including plans to issue guidance and recommendations to member states on improving independent living and inclusion in the community.

While the EU disability policy has been mostly implemented though ‘soft’, non-compulsory measures, there are also important legally binding instruments, promoting and protecting the rights of people with disabilities. The first legal breakthrough came with the signing of the Amsterdam treaty in 1997. Article 13 of the Treaty recognised discrimination on the grounds of disability, among others, empowering the Community to take actions to combat it[31]. This led to the adoption of two equal treatment directives in 2000: on Race and on Employment. The latter (Council of the European Union 2000a) established a general framework for equal treatment in employment and prohibited employment-related discrimination on several grounds, including disability. It was ‘the first legislative intervention in disabled people’s rights’ (Priestley 2007:67) at EU level, which required the states, including the accession states, to take steps to change their national legislation. The directive is important because it goes beyond the prohibition of direct discrimination, i.e., the less favourable treatment of disabled people on the grounds of disability to cover indirect discrimination and include provisions related to reasonable accommodation. The latter requires employers to take ‘appropriate measures’ to enable people to participate in employment or training, ‘unless such measures would impose a disproportionate burden on the employer” (Article 5). Thus,

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[31] For a discussion of the importance of the Amsterdam Treaty for disabled people, see European Disability Forum (1998) and Whittle (1998).

to a certain extent[32], it can be considered a positive provision as it attempts to remove barriers that exclude and disable people with impairments (Lawson 2005).

Another key step towards strengthening the rights-based perspective on disabilities was the EU Charter of the Fundamental Rights of the European Union, which was proclaimed in 2000 and became legally binding for the states in 2009. In addition to prohibiting discrimination on the grounds of disability, it underlines the importance of the measures that ensure independence and participation of disabled people in community life (Article 26 – Integration of persons with disabilities)[33]. With the adoption of the Charter, the EU 'incorporated a visible and guiding fundamental rights framework for its legislative and policy work' (Hoefmans 2012). EU member states are required to adhere to the Charter when implementing EU law.

After 2000, disability issues were addressed in several EC directives, spanning various areas, such as copyrights, procurement procedures, electronic communications, networks and services, trafficking, and transportation. This effort was part of the Community's commitment to mainstream disability, expressed in the 1996 Communication. A number of non-binding resolutions were also adopted by the Council of Ministers and the European Parliament. The Council's resolutions focused on employment and social integration, culture, education and training, and knowledge-

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[32] This is only to a certain extent because although 'reasonable accommodation' goes beyond non-discrimination, it differs from positive measures by being specifically aimed at individuals, 'it responds directly to an individual, is tailored to that individual and any failure to achieve it may trigger a suit for discrimination' (Quinn 2009:100).

[33] Other relevant provisions, although not specifically mentioning disability, include the requirement for free and informed consent in the field of medicine and biology (Art. 3), the prohibition of torture and inhuman or degrading treatment or punishment (Art. 4), the acknowledgment of the right to liberty and security (Art.5), for respect for private and family life (Art. 7), to education (Art.14), to work (art. 15), to social security and assistance (Art. 34), etc.

based society. Meanwhile, the European Parliament's resolutions[34] called on the member states to remove existing barriers and obstacles and ensure that disabled people have universal, effective, non-discriminatory access to social protection, health care and education, and to services available to the general population, such as housing, information, culture and leisure, transportation, etc.

The move towards a rights-based European disability policy culminated in the European Union's conclusion of the Convention on the Rights of Persons with Disabilities in 2010. It gave the Convention primacy over secondary Community legislation[35] (such as directives), meaning that both member states and the European Union institutions must apply EU law in accordance with the Convention on the rights of Persons with Disabilities (Parker and Clements 2012), even if the states have not yet ratified the Convention.

To sum, the EU's discourse on disability has evolved over the years, shifting from a medical to a social understanding of disability. This shift is reflected in the changing policy content, moving from a focus on rehabilitation towards promoting measures aimed at removing barriers to participation and enhancing the social inclusion of disabled people in the mainstream society. It also involves encouraging the involvement of disabled people and their organisations in policymaking at both the EU and national levels. Since the 1990s there has also been a process of institutionalisation EU disability policy as a new policy field. This involved the creation of various bodies, such as the Unit for Integration of Persons with Disabilities at the EC, the High-Level Group (HLG)

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[34] Includes resolutions on the situation of women with disabilities in Europe (2018), on the mobility and inclusion of people with disabilities (2011), and on the impact of the crisis on the access to care for vulnerable groups (2013).

[35] Within the framework of EU law, the Convention on the Rights of Persons with Disabilities is inferior to the Treaties but superior to the secondary legislation.

of Member States Representatives on Disabilities, the Academic Network of European Disability Experts (ANED). It also included, development of legislation and policy documents (strategies, recommendations, directives), production of reports, etc.

Disability policies as employment policies

In parallel with the shift towards a social and human rights approach to disability, and the growing focus of EU social policy on inclusion, disability policies have evolved from an exclusive focus on employment to a more holistic approach, addressing the range of challenges faced by disabled people., such as education, social services, transportation, housing, etc. However, until the end of 2010s employment remained central to EU disability policies. The impact of the Employment directive has been 'severely and disappointingly limited' (Lawson 2009:275) due to its restriction to employment. For comparison, the other equal treatment directive, inspired by the introduction in the Amsterdam treaty of provision related to discrimination – the Race directive (Council of the European Union 2000b) – applies to social protection, education, housing and goods and services, as well as employment.

Even when EU policy documents emphasise disabled people's inclusion, a close examination often reveals a focus on employment and the labour market (Waldschmidt 2009). Thus, despite its comprehensive coverage, the EU Disability Action Plan 2004-2005 emphasised the need to mainstream disability policies in employment because 'employment remains the primary and most effective way of creating lasting improvements for people with disabilities and of achieving their full social inclusion' (European Commission 2003b:13). As a result, efforts to integrate disability into mainstream policies mostly targeted employment-related policies, such as education and lifelong learning (Lawson 2005). Other areas, such as accessibility became important insofar as they enabled disabled people to participate in employment: ‘[a]ccessibility can make the difference between a disabled person being active in the labour market and being dependent on social welfare’ (European Commission 2007:4).

The strong orientation towards employment appears to have almost completely disappeared from the European Disability Strategy 2010-2020, where it is only one of eight priority areas, the others being equality, participation, social protection, accessibility, education, health, and external action. The reduced emphasis on employment can be linked to the EU’s evolving understanding of disability as a human rights issue, following the adoption of the Convention on the Rights of Persons with Disabilities and its ratification by the Union. This shift also led to the Disability Unit – the body dealing with disability policies at the European Commission – being moved from Directorate General for Employment, Social Affairs and Inclusion (DG Empl) to Directorate General for Justice and Consumers (DG Just) in the 2009-2014 Commission mandate. However, this move was reversed in the 2014-2019 period, despite calls from key European organisations of disabled people, such as the European Disability Forum, the European Network on Independent Living and Inclusion Europe, which argued that disability is a matter of right. The Disability Unit is currently still in DG Empl.

At the same time, the justification and the objectives of the European Disability Strategy 2010-2020 remained strongly linked to EU’s economic goals:

> ‘Full economic and social participation of people with disabilities is essential if the EU’s Europe 2020 strategy is to succeed in creating smart,

> sustainable and inclusive growth. Building a society that includes everyone also brings market opportunities and fosters innovation' (European Commission 2010b: 4).

While aiming to ensure the implementation of the CRPD, the Strategy also emphasised the need to foster disabled people's participation 'in society and in the European economy, notably through the Single Market'. The bundling of social and employment aspects, which the CRPD does not do, indicates the importance of economic objectives in the EU's approach. Similarly, the EU Charter of Fundamental Rights bundles the social and employment aspects calling for 'social and occupational integration' of disabled people (Article 26). O'Brien (2014: 738) warns that such an approach could lead to 'rather thinner, more formal conception of integration, geared at "activating" persons with disabilities'. In addition, in line with the overall orientation and priorities of the EU, the European Disability Strategy's approach to employment was underpinned by productivist ideas and centred on activation. The Commission urges the states 'to fight those disability benefits cultures and traps that discourage them [disabled people] from entering the labour market' and to 'develop active labour policies' (European Commission 2010b:8). Similarly, its predecessor – the European Action Plan 2003-2010 – promoted 'modernisation of social protection', framed as a 'shift from long-term dependency on passive welfare benefits to active labour market measures'.

Overall, EU disability policy has been strongly orientated towards employment. As Rowell (2013) notes, disability was put on the EU agenda, but it was framed as part of the EU employment strategy. In recent years, especially since the adoption of the European Disability Strategy 2010-2020, there has been a shift towards a more comprehensive approach, yet economic and employment-related arguments for disability policy still play a key role.

The focus on employment of disabled people fits well with the economic priorities of the European Union, the stress on jobs and growth and the view of social policy as a productive factor. With the changing understanding of disability, the integration of disabled people into the mainstream was viewed as an economic issue – ‘in so far as their occupational integration in a regular working environment may often represent an asset for the Community’ (European Commission 1989a:53). Disabled people, along with other groups excluded from the market, such as women, young people, minorities, and legal migrants, were seen as the ‘untapped “reservoir” of labour supply’ (Rowell 2013:11), which should be mobilised to increase the level of employment in the Union and contribute to the achievement of its economic objectives. Thus, the Disability Action Plan for 2006-2007 (European Commission 2005b) noted that the demographic situation in the Union demands that ‘the economic potential of disabled people and the contribution they can make to economic and employment growth must be further activated’. In 2013, Commissioner Viviane Reding further emphasised that the ‘the need to find new impulses for growth raises the relevance of the employment rates of all segments of population’ (European Parliament 2013) including employment rates of disabled people.

This exclusive focus on paid work as a solution to the problems faced by disabled people is problematic from a disability perspective. On the one hand, it leads to the invalidation and exclusion of people who cannot or do not want to work – they are seen as less worthwhile and valued, and at the same time, they get impoverished and marginalised

(Mladenov 2015, Patrick 2012). On the other hand, it fails to recognise the importance of other factors contributing to the exclusion of disabled people. As Gowar (2014:22) points out, it 'simply ignores how wealth cannot "buy" a disabled person out of many aspects of exclusion such as physical barriers to access, segregated education, and employment'. Thus, even when EU policies address structural barriers to inclusion (e.g., related to accessibility), the employment and productivity perspective towards inclusion risks leading to reduced efforts to address these structural factors. In addition, this strong focus on improving employability of disabled people, in the context of EU's active promotion of austerity policies, suggests that 'the Commission treats disabled people as targets for welfare reduction without engaging with the specific issues of social care services, or of inability to work or inability to find work' (O'Brien 2014:739-740).

EU's engagement with NGOs – development and underlying assumptions

The NGO sector began to gain importance for the EU at in the late 1980s and early 1990s. The were two primary ways the EU engaged with NGOs. The first was in the context of the single market and social economy, and the second focused on participative democracy where NGOs acted as a part of civil society (Charrad 2014). This latter approach was important both within the European Community and internationally. It was used to address the EU's democratic deficit and to promote democracy it's the enlargement process (Borragán 2016).

NGOs and social economy

During the late 1980s and early 1990s, under Jacques Delors' presidency, the EU began to view NGOs as key players in the social economy. Delors viewed NGOs as 'an EU policy instrument for strengthening economic development, and also for coping with the employment problem' (Kendall et al. 2009:348). In 1989, social economy gained institutional recognition at the EU level with the establishment of the Social Economy Unit in Directorate General XXIII[36]. That year the EU started shaping the sector's policies with the EC communication entitled 'Businesses in the "Economie Sociale" sector: Europe's frontier-free market'. It highlighted NGOs' engagement in productive activities emphasising their economic significance (European Commission 1989b). Whether NGOs produced goods for the market or non-market services, they were seen as competitors to traditional businesses (European Commission 1989b).

The focus on the economic contribution of third sector organisations (associations, foundations, co-operatives and mutual societies) as an instrument for labour market policies gained momentum at the end of the 1990s with the adoption of the European Employment Strategy, which encouraged the creation of jobs in the area of social economy (Entrepreneurship pillar, Guidelines 8 to 12). After Lisbon, the role of third sector organisations in relation to economic development and the fight against unemployment and social exclusion was increasingly stressed, and their potential to address the labour market problems, including when it comes to supporting the employment of vulnerable groups, such as disabled people, was highlighted (Zimmer and Hoemke 2016). Thus, the European Parliament (2009: para 20) stressed that

> 'the social economy helps to rectify three major labour market imbalances: unemployment, job instability, and the social and labour-market exclusion of unemployed people; […] the social economy plays

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[36] The Unit was restructured in 2000 and its responsibilities were divided between DG Enterprise and Industry and DG Social Affairs (European Economic and Social Committee 2012).

> a role in improving employability and creates jobs that do not normally delocalise'.

The promotion of social economy has continued in the recent years. For example, in December 2015 the Council of the European Union (2015:4) adopted Conclusions on the Promotion of Social Economy as a Key Driver for Economic and Social Development in Europe, noting that social economy 'constitutes an important pillar notably in terms of employment and social cohesion across Europe and which is also key to achieving the goals of the Europe 2020 Strategy'. The development of social economy as an instrument in the fight against poverty and social exclusion was also underlined by the EC in its Communications concerning the Single Market Act (European Commission 2011a) and Social Enterprises (European Commission 2011b).

NGOs and the democratisation in the Central and Eastern Europe

Following the fall of the state socialism, NGOs became increasingly discussed in the context of democratisation, with a focus on CEE countries (European Commission 1997b and 2000a). Due to the legacy of strong and centralised state major goal during the early transformation efforts in CEE was to 'dismantle the central government control inherited from the communist system' (Economic and Social Committee 1999: 4). Establishing a public sphere, where citizens could voice their interests and challenge state power was seen as essential. NGOs had an important role to play in this process as a tool for citizen's empowerment. Thus, at the beginning of the 1990s, as a part of the Western efforts to support democracy, the EU (through its PHARE programme) and other international donors started funding NGOs. Initially, the EU's financial assistance sought to create 'a moral community in all these countries, including groups and individuals who are essential to the construction of a democratic political culture, who lobby for democratic change and who constitute an ongoing form of public discussion and education' (ISA Consult et al. 1997:II).

However, looking closely at the type of civil society promoted by the EU and other foreign donors, Fagan (2005) notes that the initial focus on participation and representation was soon replaced by a stress on professionalisation, as foreign donors sought to build the capacity of NGOs to become partners in the policy process. He argues that this partnership role of NGO fits well with the neo-liberal agenda of transforming state power and freeing capital. From this perspective, whether NGOs are viewed as partners, watchdogs or service providers, their main function is to strengthen the status quo, restrain and transform state power and take on many of state's functions – 'a kind of political *laissez-faire*, the political equivalent of neo-liberalism' (Anheier et al. 2001:11). They are not seen as 'vehicle for serious political critique, for challenging economic and political hegemony, or for transforming state–society relations' (Fagan 2005: 531).

Raik (2006) has also explored the assumptions underpinning the EU's promotion of civil society in the CEE, but within a different framework. She identifies three main models of NGOs as civil society[37] – partners of the state, substitute for the state, and critical counterweight to the state. In the first, the role of NGOs is to assist the state with its governance tasks. NGO-state relations are characterised by cooperation and inclusion, for example, though participation in different commissions and other bodies, and joint

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[37] She also includes a fourth category – NGOs as recipients of aid, which, however is not related to a specific conception of civil society.

projects. The substitute of the state model is based on the neo-liberal thought, in which the individual freedom and the free market are central. In this model, the role of the civil society is to take over social functions from state institutions and thus to help minimise the state. The relation to the state is one of contracting and producing services. The third model, civil society as critical counterweight, has its roots in the liberal participatory and critical theories, which emphasise the political function of civil society and the control over state power. The role of civil society is to ‘act as an independent, critical force that represents in public the different groups and identities that exist in society’ (Raik, 2003: 330). Relation of civil society to the state is one of criticism, control and pressure. Raik finds that the EU has influenced most directly, through funding and recommendations, the understanding of NGOs as partners of the state in the public policymaking. The model of NGOs as a substitute for the state has not been explicitly promoted by EU institutions, but EU funding programmes have positioned NGOs in such a role. Finally, the EU’s influence on the watchdog role has been mainly indirect, that is through diffusion of norms and models.

In the second half of the 1990s the EU’s strategy for NGO development became increasingly focused on preparing countries for EU membership. This shift in the priorities is reflected in the renaming of ‘PHARE Democracy’ programme to ‘PHARE Accession’. A turning point in the EU’s support for civil society development came with the 1993 Copenhagen Council, which set out the economic and political conditions necessary for CEE countries aspiring to join the EU. Beginning 1995, with the signing of Accession Partnerships between the countries and the EU, the Phare programme became ‘accession-driven’ incorporating components related to the adoption of the *acquis Communautaire* (European Commission 1997a). By 1999, it was ‘fully reoriented towards the accession objectives in the Accession Partnership and National Programme for the Adoption of the Acquis, as redefined annually by the Regular Reports and Negotiations' (European Commission 2000c). NGOs emerged as important tools for policy development and good governance.

The promotion of civil society continues to be an important element of the EU's external policy after the 2004-2007 accession, becoming more prominent over the years (Buzogány 2018). Almost a decade after the accession of the first CEE countries, two perspectives persist within the EU's discourse: NGOs contributing to democratisation and NGOs as instruments for state effectiveness. For example, in its communication 'The roots of democracy and sustainable development: Europe's enlargement with Civil Society in external relations', the Commission (2012:3) highlights the role of NGOs in articulating citizens' concerns in public and furthering participatory democracy. At the same time, it acknowledges that their participation in the policy process is key for ensuring effective policies. NGOs continue to be seen as vital for the successful implementation of EU requirements. However, there has been a shift in the EU's narrative in recent years, from NGOs as partners of the state, towards NGOs as watchdogs, controlling the state on behalf of the EU (Buzogány 2018), i.e., NGOs as partners of the EU.

After the CEE countries' EU accession, which confirmed their successful transition to liberal democracy and a free market economy, there have been no specific EU policies targeting NGOs in these countries, nor separate funding routes. Post-accession, the role of NGOs has shifted to supporting the implementation of certain EU policy priorities. This includes promoting EU values and strengthening the legitimacy of EU institutions (as discussed in the next section), as well as acting as partners of the state to support the development and implementation of national policies in line with EU's requirements (for example, in the context of the European Union funds).

NGOs and EU's democratic deficit

The EU's second form of engagement with NGOs in the framework of democratisation concerned its own democratic deficit. The growing dissatisfaction with the EU's 'democratic deficit'[38] and the Europeans' alienation from its work led to calls for bringing European institutions closer to EU citizens (European Council 2001). The European Commission (2001a:11) admitted that the EU's legitimacy depends not just on economic matters but on active citizen involvement. This shift towards greater participation internally mirrored similar approaches in the EU's external policies (Buzogány 2018).

The gradual EU turn towards civil society, which began in the 1990s (Smismans 2009; Quittkat and Kohler-Koch 2013), intensified at the beginning of the new millennium with the publication of a European Commission discussion paper on building stronger partnerships with NGOs. The paper recognised NGOs as a 'significant component of civil society' and acknowledged their role in 'fostering participatory democracy both within the European Union and beyond' (European Commission 2000a:4). The White paper on European governance, adopted in 2001, further 'elevated civil society to the position of key actor in the democratisation of the EU' (Quittkat and Kohler-Koch 2013). In 2007, with the adoption of the Treaty of Lisbon, the participation of civil society

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[38] This refers to the 'conceptualisation of the Union as an elitist, international organisation where decisions are reached by unelected policy experts who are not accountable to elected representatives, while laws are passed with little transparency and publicity' (Borragán 2016: 251).

organisations at the EU level and the direct engagement of citizens[39] were enshrined in the EU's primary law. Article 8B of the Lisbon treaty[40] obliged EU institutions to 'maintain an open, transparent and regular dialogue with representative organisations and civil society'. The EU saw this change as a step towards strengthening democracy by introducing the principle of participatory democracy in addition to the principle of representative democracy (EUR-LEX 2017).

Although highlighting its importance for democracy, the EU looks at civil society mostly as an instrument to enhance the legitimacy of EU institutions and the European integration project and the effectiveness of its policies (Magnette 2001, Buzogány 2018, Smismans 2013). The role assigned by the EU to civil society, generally understood to mean organised civil society, is one of a 'transmission belt' (Zimmer and Hoemke 2016, Kohler-Koch 2009). On the one hand, NGOs are seen as important actors in the EU's communication policy because they can facilitate the delivery of information from the EC institutions to local and national levels, thus 'closing the gap' between the EU and its citizens (European Commission 2006c) and ensuring better understanding of and support for its policies. For the EU, adequate information and effective communication are for the EU 'a pre-condition for generating a sense of belonging to Europe' (European Commission 2001a:11). On the other hand, NGOs can voice the concerns of the specific constituencies they represent to the EC (European Commission 2001a), which is expected to contribute to more efficient governance (Magnette 2001, Kohler-Koch and Quittkat 2013). Thus, the Commission stresses that participation can enhance 'the quality, relevance, and effectiveness of EU policies', contribute to 'more effective policy

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[39] The Treaty of Lisbon introduced the 'European citizen initiative, which allowed EU citizens to invite the Commission to propose a legal act to implement the EU Treaties.

[40] In the consolidated version of the Treaty on the European Union, this is Article 11.

shaping' (European Commission 2001a:15) and can 'ensure that proposals put to legislature are sound' (European Commission 2002a). This is expected to strengthen further the legitimacy of the Union – to 'create more confidence in the end-result and in the institutions, which deliver policies' (European Commission 2001a:3) and 'win public acceptance for the EU' (European Commission 2000a:5).

Both of these functions of NGOs – communication and participation in policymaking – presuppose the establishment of partnership relations with the EC (European Commission 2001 and 2006c). Thus, akin to the EU's external policy, NGOs are included in a partnership framework. Despite the rhetoric of democratisation, they are used as instruments to achieve the EU's goals related to securing the legitimacy and effectiveness of its policies and the European integration project. As Kohler-Koch (2009:55) writes, while 'European citizenship is a cherished concept in the EU, it is not linked to the idea of a politically active European civil society'. The instrumentalisation of NGOs has a negative impact on NGOs willingness and ability to criticise because, as Smismans (2009:65) notes, they are 'not supposed to be a critical voice entirely against policy initiatives or the European construction as such'. He further warns that this may lead to the institutional capture of NGOs, related to their access to funding, or to the neglect of the more critical voices by the European Commission.

Conclusion

This chapter explored EU policies on disability and NGOs, along with their underlying assumptions. In terms of disability policy, reflecting the paradigm shift in the field of disabilities, EU's understanding of disability shifted from a medical perspective focus on rehabilitation and sheltered employment towards a more social one. This new approach prioritises the inclusion, participation rights of disabled people. At the same time, disability policy has also been subordinated to EU's economic objectives. It has stressed employment – and the role of disabled people's work in supporting EU growth and competitiveness. These two perspectives – a broader human rights view and a narrow economic focus – have co-existed in EU disability policy. The human rights agenda has become more prominent in recent years, following the adoption of the CRPD.

Reflecting EU's inherent contradictions, EU's engagement with NGOs have also been motivated by different agendas, including economic development, but also democratisation and enlargement. During the CEE countries' accession, there was an emphasis on the role of NGOs as partners of the state in the policy process, which aimed to ensure stability and effectiveness of the policy process and legitimacy of policies and institutions. However, this partnership role, which prioritises consensus and compromise over criticism and conflict, threatens the potential of NGOs to seek radical transformation in policies. Similar challenges are faced by NGOs working at the EU level, which have been instrumentalised by the EU to enhance its legitimacy. At the same time, the economic perspective towards NGOs as part of the social economy contributes to their depoliticisation by putting them in the role of 'business enterprise', 'employer' or 'service provider'.

Chapter 3: The Bulgarian Case

The chapter seeks to provide a contextual background on disability policy and NGOs in Bulgaria, tracing their development through the years of state socialism and the 'transition' period to the present. It begins by examining disability legislation and policies, exploring key measures and approaches to solving the challenges faced by disabled people and the understanding of disability underpinning these approaches. As the research aims to analyse the interrelationship of disability policy and NGOs willingness and ability to influence policy, the second part of the chapter shifts the focus towards NGOs as actors in the policy process, with a particular focus on organisations working in the disability area.

Disability policy and understanding of disability

Bulgarian social policy started developing at the end of 19th century when the country gained its independence from the Ottoman Empire, following nearly 500 years under its rule. After liberation, the new Bulgarian state lacked the financial and organisational capacity for a systematic social policy (Nikolova and Stoyanova 1997). As a result, support for disabled people primarily came from private charity organisations and initiatives. Typically, this involved providing food, clothes, and medicines, organising soap kitchens, setting up and maintaining kindergartens, schools and social care institutions like orphanages, and institutions for people with impairments, and arranging sheltered employment for disabled people. The first law regulating the provision of public assistance, the Public Assistance Act (*Naredba-zakon za obshtestvenoto podpomagane*), was adopted in 1934. It defined public assistance as consisting of: (1) the provision of material and, in exceptional circumstances, financial support, or (2) placement in one of the ‘places for public assistance and charity’, meaning a social care residential institution. The Law established a special Fund for Public Assistance and a Public Assistance Service under the Minister of Internal Affairs and Health, tasked with leading and coordinating public assistance initiatives in the country, including establishing or closing social care institutions. However, the public assistance system continued to rely heavily on charitable support from individuals and foundations. The main responsibility for establishing and supporting social care institutions lay with the municipalities.

State-socialism

The current disability policy in Bulgaria and other CEE countries is strongly influenced by the legacy of the state socialism and the transition towards democracy and a market economy (Rasell and Iarskaia-Smirnova 2014, Mladenov 2017 and 2018). This policy reflects the dominant during state socialism understanding of disability, along with ‘global dynamic beyond (post) socialism, for example neoliberal retrenchment and human rights discourses’ (Rasell and Iarskaia-Smirnova 2014:4).

State socialism was characterised by a state-owned and centrally planned, rather than driven by supply and demand economy, with regulated prices and no competition. Full employment was a priority, linked to industrialisation and economic growth, requiring the involvement of the entire working-age population. Politically, a one-party rule was established, placing both the economy and society under the control of the party, which was essentially equivalent to the state.

During state socialism, disability policy was underpinned by strong medical and productivist understanding of disability as ‘inability to work caused by medically identifiable bodily or mental deficiencies’ (Mladenov and Petri 2020a). In line with this understanding, the main types of support for disabled people included: (1) work placement and community service involvement, (2) placement in social care institutions and (3) provision of benefits (1951 Decree on Public Assistance). Access to state-provided benefits and services was determined by assessment from ‘medical labour-expert commissions’ (*lekarski trudovo-ekspertni komisii),* which put people in three categories based on their inability to work – a system that is still in use today.

Under the medical-productivist paradigm, policies pursued two goals. First, they aimed to ‘readjust’ (Golemanov and Popov 1976:30) disabled people to society, through sheltered employment. Second, they sought to hide them in residential institutions, where they often received low-quality care. In the first thirty years of the regime, there was almost six-fold increase in the number of residential institutions in Bulgaria– from 25 facilities with 915 beds in September 1944 to 142 settings with 13,700 beds by the early 1970s. Further expansion was planned to ensure that ‘[e]very district will have effective welfare establishment with great capacity’ (Golemanov and Popov 1976:33). These institutions, often located in remote areas, were the only form of support for disabled people needing assistance but unable to rely on relatives. However, their remote location often meant inadequate care and support and limited opportunities for participation in society. This system of residential care also allowed the state to present and image of addressing citizens’ needs while keeping them out of public view, creating an illusion of a society free from social problems (Phillips 2009).

For disabled people assessed as capable of working, sheltered workshops in the form of special enterprises or cooperatives were built. Between 1955 and 1964, the number of these workshops increased more than seven times (from 9 to 64) and the number of people employed there rose from 372 to over 22,000 (Golemanov and Popov 1976). In the 1960s, some sheltered workshops were expanded to include blocks of flats and additional facilities, such as nurseries, medical and dental centres, cultural centres, and canteens, forming '*proizvodstveno-bitovi'* complexes (from *proizvodstvo* – production and *bit* – related to the living). While providing jobs, these complexes reinforced disabled people's isolation, turning into 'ghettoes' (Sotirov 2004: n.p.). Furthermore, the jobs offered predominantly involved low-skilled, manual labour.

The growth sheltered workshops and residential institutions during state socialism was primarily driven to productivist goals. On one hand, residential institutions enabled family members of disabled people to keep work, preventing the loss of workforce. On the other hand, sheltered employment and employment related services (vocational training and assignment to lighter jobs) allowed the state to utilise 'the reserve' (Golemanov and Popov 1976:29) of disabled people ensuring there are less 'lost' days for the economy. This perspective, retrospectively, aligns with the EU's later view of disabled people as 'untapped potential for the development of economic growth' (European Commission 2003b:7).

The isolation of disabled people in segregated settings was a common feature of social care systems in Eastern socialist countries (Rasell and Iarskaia-Smirnova 2014, Holland 2008, Phillips 2012). However, this approach to disability was not unique to these countries. In the first half of the 20th century, institutionalisation was also the primary form of care for disabled people in western capitalist countries (Noll 2018), a practice linked to the development of industrial capitalism (Oliver and Barnes 2012). As Mladenov and Petri (2020a:5) write, ‘the difference was in degree rather than in kind – the enhanced industrialisation sought by the state socialist regime conditioned a greater emphasis on the productivity enhancing functions of segregated provision’. Only in the 1960s, influenced by the civil rights movement, did the collective mobilisation of disabled people begin (Sabatello 2014). The dominant medical understanding and approaches to disability in the USA and some European countries began to be questioned and gradually change. In Bulgaria and other CEE countries, the oppressive regime made in impossible for disabled people to organise politically and challenge exclusionary policies and practices (Rasell and Iarskaia-Smirnova 2014:6), so the medical model and the interventions informed by it continued to exist and spread.

Interestingly, Bulgarian policymakers were aware about the developments in the West, as demonstrated by Golemanov and Popov’s 1976 book on social policy in Bulgaria. The authors present a rather progressive vision of the future Bulgarian society where people with severe impairments are able to *participate* actively in the social and cultural life with the help of technical aids and architectural accessibility. This future, however, did not materialise during state-socialism and residential institutions remained the main type of support for disabled people. The only community alternative to institutionalisation, introduced in the 1970s as a pilot initiative, was the ‘social patronage’. It involved daily provision of food, services, and medical care to disabled and older people in their homes. However, the support provided was limited and did not allow people with complex needs to avoid institutionalisation. In addition, many people who remained in their homes thanks to the social patronage, still faced isolation from the wider community. The service was not designed to support active participation but merely to satisfy basic needs like food and health.

Post-socialism

With the end of state socialism in October 1989, Bulgaria began its transition from socialism to capitalism, a free market economy, and liberal democracy, along with preparations to join the EU. This transition had a strong negative impact on the capacity of social policies to support the inclusion and participation of disabled people. The radical economic reforms towards privatisation, decentralisation, and price and trade liberalisation were accompanied by a rapid escalation in unemployment, collapse of incomes, sharp increase in poverty and decrease in the standard of living (World Bank 2003). ‘Poverty in all its forms (absolute and relative, total and partial, lasting and temporary, objective and subjective) has increased practically everywhere’ (Ferge 1998:12). Many disabled people lost their jobs as shelter workshops were forced to close or reduce their capacity, while the inflation and skyrocketing prices made disability benefits inadequate to meet even basic needs. The social problems caused by economic restructuring accelerated the marginalisation of disabled people and reinforced the stigma accompanying disability (World Bank 2003).

Together with this, the reforms diminished the state’s redistributive capacity, leaving it with limited resources to meet the numerous social challenges of the transition, including to invest in supporting disabled people’s inclusion and participation (Rasell and Yarskaya Smirnova 2014, Ferge 1998). In addition, expenditures on social services were cut (Cox 2020), which further worsened disabled people’s access to social and health services and led to deterioration of the quality of already existing services.

The numerous challenges of the accession meant that little attention was paid to reforms of disability policies and practices. In the 1990s, the only policy document in the area of disabilities was the Protection, Integration, and Social Rehabilitation of Invalids Act (1995). This was also Bulgaria's first comprehensive disability legislation. Its adoption was mainly driven by the need for a comprehensive policy document rather than a new approach. This the Act sought to confirm the role of the state in providing financial assistance to disabled people in a context of deep economic, social, and political transformation of the country. It reproduced traditional views, despite its stated aim being 'to create conditions for social integration of invalids and for their full and equal participation in society' (Art.1(2)). Some of its progressive provisions, like those about accessibility and inclusive education, remained on paper, due to the lack of relevant legal framework and instruments for implementation.

Through the 1990s, support for disabled people continued to be dominated by institutional care. A limited number of alternative community services also existed, established, and provided by domestic and foreign NGOs, supported by external funding[41]. Reflecting these developments, the adopted in 1998 Social Assistance Act expanded the range of support options by adding new services alongside those inherited from the state socialism. In doing so, it sought to regulate services already provided by NGOs rather than to promote new types of services. However, no state funding was secured to support the creation and existence of these new services. Moreover, the goal of the services was narrowly focused on satisfying basic needs, understood as 'sufficient food, clothing and housing' (Art.16).

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[41] However, due to project-based funding these services were usually short-term and unsustainable.

After 2000, began a gradual turn towards ideas related to social inclusion, participation, and human rights. This change was largely influenced by the developments at EU level and the Convention on the Rights of Persons with Disabilities (see Chapter 2). In 2002-2003, several important amendments were made in the Social Assistance Act. Social inclusion, defined as 'creating conditions and opportunities for participation in the public life' (Art. 31, 1, 3), became a key goal of social services, thus overcoming the law's initial narrow understanding. The trend of expanding support options continued as new services, including personal and social assistant, were added to the list of social services. Distinction was also introduced between institutional and community-based services. The latter were given priority and institutional care was seen as a last resort (art. 36 (4)). The diversification of services was further promoted by changes in funding, allowing private organisations to receive public funding to deliver services (see section NGOs in Post-socialist Bulgaria below).

In 2005 the Integration of People with Disabilities Act was adopted. Even it's the critics of the law regarded its objectives as 'completely in the spirit of human rights instruments' (Panayotova and Todorov 2007:5). This law replaced the term 'invalids' with 'people with disabilities' and demonstrated a 'contemporary and comprehensive understanding of the term 'integration[42]' (Panayotova and Todorov 2007: 6). It introduced a social assessment of disability, alongside the existing medical one, aiming to ensure that individual needs and preferences are taken into account.

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[42] The law used the term 'integration' rather than 'inclusion' to describe disabled people's participation in community. At that time, 'integration' was commonly used in domestic, EU and international policy and advocacy alongside 'inclusion'. However, proponents of the social model of disability challenged its use, starting with a focus on education. They associated 'integration' with policies that placed children in mainstream education and expected them to adapt to the pre-existing structure. In contrast, 'inclusion' referred to policies seeking to change education delivery system to accommodate differences (see Stubbs 2008). Over time, the term 'inclusion' has gradually replaced 'integration' in all areas disability policy.

However, the medical understanding of disability continued to dominate legislation and attitudes of society and of policymakers. In 2007, in response to the critiques of residential institutions, the then Minister of Labour and Social Policy, Emilia Maslarova, stated:

> ‘It is time to understand that when some people, children or adults, are with severe mental disabilities, they will not begin to speak or read. They just do not have any capacity. […] Of course, we do not have super conditions, but these are children that can do only that much, only that much’ (Maslarova 2007).

Following Bulgaria’s ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2012, the human rights discourse on disabilities was further strengthened. The 2018 Disabled People Act, which replaced the Integration of People with Disabilities Act, incorporated many of the Convention’s key principles, including an emphasis on independence, choice, social inclusion, and full participation. It also borrowed from the Convention the definition of people with disabilities, shifting the attention to the role of environmental barriers in hindering disabled people’s inclusion and participation in society[43]. The Personal Assistance Act, adopted in the same year, and the Social Services Act also have strong human rights and social inclusion perspectives.

However, as the medical understanding of disability continued to dominate, disability

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[43] According to Article 1 of the CRPT, persons with disabilities ‘are persons with physical, psychological, intellectual and sensory impairments, which in interaction with the environment may hinder their full and effective participation in society’.

legislation evolved into a mixture of progressive language and provisions alongside traditional approaches and measures. For example, the social assessment of disabled person’s support needs, introduced by the Integration of People with Disabilities Act, continued to rely on the decision of the Expert Labour-medical Commissions and was guided by medical criteria. The new Disabled People Act kept the central place of the medical assessment. Together with the CRPD-informed definition of ‘people with disabilities’ mentioned earlier, the Act adopted a definition of ‘people with permanent disabilities’, incorporating a requirement for medical assessment into the CRPD definition. As the term ‘people with permanent disabilities’ determines the access to disability support in Bulgaria, the broader definition of ‘people with disabilities’ ‘functions only as a mechanically added ornament’ (Mladenov 2021).

In addition, the implementation of the new policies faced various challenges, indicating that these measures were only adopted formally, to demonstrate commitment to reform, rather than real intention for change – a common pattern of superficial top-down Europeanisation (Sedelmeier 2011). For example, many legislative reforms included in the action plans for implementing the CRPD (2013-2014 and 2015-2020) were delayed or postponed (Bulgarian Helsinki Committee 2017). The implementation of the strategies and/or action plans for disabled people (2003-2006, 2008-2015 and 2016-2020) and for employment of disabled people (2011-2020) was hindered by the lack of specific and adequate funding allocations. The government eventually acknowledged that this was a key problem in its policymaking (Council of Ministers of the Republic of Bulgaria 2014). The social partners also criticised the formal character of the strategies noting that ‘the lack of specific mechanisms and financial instruments for the realisation of the measures, make the adoption of the Strategy [for Equal Opportunities of Disabled

People, 2003] pointless' (National Tripartite Cooperation Council 2003). Although the country's access to EU funds in 2007 helped secure resources to support the realisation of strategies, issues with formal and delayed implementation continued. Thus, the Action Plan for the Implementation of the Strategy for Long-term Care, setting out the specific activities, timeframe, and resources, was only adopted in 2018, four years after the Strategy. One of the few strategies, if not the only one, with adequate funding and implementation was the National Strategy 'Vision for deinstitutionalisation of children in the Republic of Bulgaria' (2010-2025), which led to the closure of many traditional institutions for children.

In sum, despite the numerous changes in the regulation, organisation, and provision of support to disabled people, little changed in the approach to provision and the related to it attitudes and practices, which remained paternalistic and segregating. At the beginning of 2020s, there is still a wide network of institutions for disabled people, providing inadequate care. A recent report by the Council of Europe's Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (2020) strongly criticised the country for the practices of physical ill-treatment by staff, the use of illegal seclusion and restrain, lack of proper individual and personalised care, and the limited opportunities for contacts with the outside world in these settings. Although most large-scale traditional institutions for disabled children closed between 2010 and 2016, this did not result in better inclusion as the majority of children were simply moved to smaller residential setting (group homes), still institutional in character – '[t]he big institution in the small village turns into a small institution in the big town' (Deneva and Petrov 2016:20). Despite the introduction of hundreds of new services, disabled adults still lack adequate support for living and inclusion in the community. Research by the

EU Agency for Fundamental Rights (FRA 2017:16) shows that in Bulgaria nearly 40% of disabled people feel left out of society, with the average for the EU being 16%.

Emergence and development of Bulgarian NGO sector

This section sets out the context for the analysis in Chapter 5 of NGOs' willingness and ability to foster domestic change. It explores the emergence and development of Bulgarian NGO sector, particularly focusing on 'disability organisations, and the legal framework related to NGO's participation in the policymaking process.

Emergence of NGOs (1878 – 1944)

The first NGOs in Bulgaria emerged in the second half of the 19th century, when the country was still under the Ottoman Empire's rule[44]. After the liberation of Bulgaria in 1878, their development and growth continued, with numerous organisations being stablished. They united people based on their professional affiliation, interests (e.g., sports, art, culture), place of residence, etc. (Gorchilova 2010a, Valkov 2009). Many soon joined together in federations and unions to increase their reach and impact. In 1933, Bulgaria passed its first law governing NGOs, the Legal Entities Act, which outlined the regulations for their registration and operation.

Organisation of disabled people began to form relatively late, after 1910. The first disability organisations were primarily self-help, single impairment groups. Their views and approaches to addressing disabled people's problems were typical of that time. A main priority for many was to improve the material situation of their members by providing financial assistance, supporting them to engage in employment or advocating

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[44] Ottoman Empire rule in Bulgaria lasted from 1396 to 1878.

for state support (for example, pensions or concessions for using public transport). Various charitable events were organised to raise funds for the organisations and for financial assistance for their members. During that period, the first sheltered workshops were established. Special institutions were promoted as a solution for those who could not support themselves financially or needed care. Some more progressive organisations also sought to raise the awareness of society about disabled people's problems and achievements by publishing articles in mainstream newspapers and distributing journals, brochures, and leaflets.

The first organisation of disabled people, the 'Invalid' association, was established in 1913, uniting physically impaired 'war invalids'. The membership and geographical coverage of the organisation grew rapidly in the following years[45]. In 1919 – 1920 were established the first organisations of people with visual impairment – the Union of Bulgarian Blind, founded by alumni of the State Institute for the Blind, and 'Darkness' – uniting those 'blinded in war'. By the end of the 1930s, the former had more than 1000 members, the latter – more than 100. The first organisations of deaf people – Association of the Deaf and Dumb – was established in 1934 by alumni of the State Institute for Deaf-Mute. It reached 200 members in 1939 (Valkov 2009).

The self-organisation of disabled people was influenced by several external and internal factors including an increase in their numbers due to the wars Bulgaria fought between 1912 and 1918; their challenging situation after the war and during the 1929 – 1936 economic crises; limited and unsystematic state support, especially during wars and

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[45] By the end of 1914, there were already 20 similar organisations at the local level. In 1915, they came together to form the Union of societies 'Invalid' (Union of war invalids and injured in wars n.d.). By 1933, the number of such societies had grown to 234, with a membership totalling 46,129 people (Valkov 2009).

crises; and a developing sense of community among disabled people in special educational institutions or rehabilitation institutions. The experience of other disabled people around the world also had important influence on some organisations. Thus, the encounter with well-educated people with visual impairments from Europe and the subsequent correspondence with visually impaired activists from various European organisations of people with visual impairments gave the inspiration and the confidence for the creation of one of the most prominent and progressive organisations at the time – the Association of Bulgarian Blind (Nenkov 2001 [1957]).

The years of state-socialism (1944 – 1989)

During state socialism, the society 'was totally patronised and controlled by a party that was equivalent to the state' (Giatzidis 2002:6). Following Lenin's idea of mass organisations as 'transmission belts' running from the vanguard to the masses, these organisations were used by the party to shape political attitudes and behaviour (Gavrilova and Elenkov 1992; Ekiert and Foa 2011). Yet. they were not just tools for social control. They also educated people and provided public services, similar to Western NGOs. Some could even represent group interest and influence policies and practices[46], although to a very limited degree.

Initially, the legal base regulating the existence and functioning of organisations was quite liberal. The new Constitution (1947) allowed citizens to from societies, associations, and organisations 'as far as they did not oppose the state and social order'. The 1949 Persons and the Family Act, however, gave the state more control over

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[46] For example, trade unions lobbied successfully for the introduction of a system for registration of unemployed workers and the provision of small temporary financial assistance (Migev 2010).

civil organisations. Despite that, many associations remained active until the end of the 1940s[47]. In the early 1950s, as Bulgaria adopted the Stalinist model[48], there was a marked shift in the state policy towards civil society organisations. A 1951 Decree for Public Assistance was adopted mandated the liquidation of all charitable associations and foundations should be liquidated, with their capital redistributed by the state. Many organisations were either dissolved, forcefully merged, or brought under party-state control. The only organisations that survived were those that 'complied strictly with the ideological restrictions while at the same time, served as vent for the citizen's initiative' (Gorchilova 2010a:105), usually cultural, educational and sports organisations. Similar trends were observed in other CEE countries (Ekiert and Foa 2011).

Organisations of disabled people had different fates during the years of state-socialism. The Association of the Deaf and Dumb, later renamed to Union of the Deaf and Dumb, survived the purges unaffected. The three main organisations of people with visual impairments were merged in 1950-1951 into a Common Union of the Blind in Bulgaria. The organisations of people with physical impairments were the most severely affected. The Union of societies 'Invalid' was closed down and its property was confiscated. Thus, at the beginning of the 1950s there were two main organisations of disabled people in Bulgaria: the Common Union of the Blind, and the Union of the Deaf and Dumb[49]. At the very end of the regime, in May 1989, the Politburo of the Communist party allowed an organisation of people with physical disabilities to be established. The organisation, the

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[47] This relatively liberal policy can be explained by the still unsettled international situation in the aftermath of World War II, and the desire of the new rule to gain popular support in the first years after coming to power (Gavrilova and Elenkov 1992).

[48] Bulgaria was 'the most loyal satellite' of the U.S.S.R. (Baeva, 2010). Unlike Hungary and Poland, it did not seek to challenge or reform the Soviet model, as there were no pressures from below to make concessions and devise forms of 'reform communism'.

[49] In 1955 the Common Union of the Blind changed its name to Union of the Blind and in 1947 the Union of the Deaf and Dumb became Union of the Deaf.

Union of Invalids, was established officially in December the same year, after the fall of the regime.

Like all organisations during state socialism, those of disabled people primarily engaged in non-political activities related to recreation, rehabilitation, and employment. In line with the official state policy promoting special enterprises and co-operatives of disabled people as the main form social care, the two unions actively started developing these enterprises (sheltered employment enterprises) in the 1950s. The state encouraged and supported the business activity of the unions with various preferences, including tax allowances, monopolies, and access to secured national and international markets (Union of the Blind, n.d.).

At the end of the 1950s – beginning of the 1960s, as part of the general process of liberalisation following Stalin's death, state policy shifted to 'encouraging some independence' (Gavrilova and Elenkov 1992:92) of organisations. In the following years some old organisations were revived, and many new ones were created in the areas of culture, sports, and science. However, since social assistance was seen as a state responsibility and regulated accordingly, the number of organisations working in the social area remained limited to the Bulgarian Red Cross and the two unions of disabled people (Gavrilova and Elenkov 1992).

The growth of organisations continued in the 1970s, boosted by new ideas promoting a growing role of public (*obshtestveni*) organisations and closer state-public cooperation. These ideas were influenced by the regime's internal problems, like economic decline. and the rise in NGO activities and membership in the West (Prodanov 2003). The 1971

The Constitution stated that the state would increasingly rely on public organisations for various tasks, aligning with Western/liberal views of NGOs as service providers, but within the communist party's political and ideological limits. This collaboration covered areas such as arts and culture (Art. 26), health education and sports (Art. 47), nature protection (Art.31), law enforcement (art. 8), and youth development. As a result, organisations of intelligentsia (artists, architects, writers, translators, composers) gained significant strength and resources[50]. The 1971 Constitution also officially allowed public organisations to carry out business activities (Art. 20, (2)).

The development of public organisations was (selectively) encouraged and supported by the state, including through generous subsidies. While the state was the main source of funding of these organisations, some also received income from membership fees and donations (Genov and Krasteva 2001). Other, such as the unions of disabled people, benefited significantly from the development of business activities. Still, despite the liberalisation of the regime, public organisations remained under the control of the party and their work was 'heavily regulated to make sure it did not contradict the state's ideology' (Smith et al. 2018:296).

NGOs in post-socialist Bulgaria

This section begins with an overview of the NGO sector's development and the legal framework governing its operations in post-1989 Bulgaria. It pays particular attention to the opportunities for policy influence though advocacy and the institutionalisation of NGO involvement in policymaking. The second part discusses the various types of

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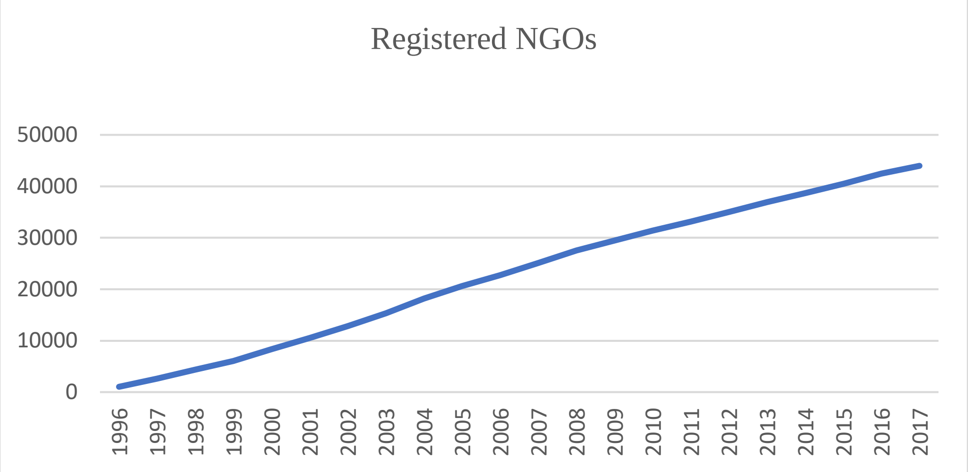
[50] Some scholars have linked the state-supported flourishing of organisations of the intelligentsia, which became particularly strong and well-resourced in the 1970s, to the delayed, dissident activities in Bulgaria compared to other countries, (Prodanov, 2003:106). While many CEE countries saw dissident activities in the 1970s, in Bulgaria it was only in the mid-1980s, and the dissident movement did not play a significant role in toppling the regime.

organisations working in the disability sector and outlines their main activities.

With the end of state socialism and the state's withdrawal from its dominant role in the political, economic, and public life, a variety of civic associations began to emerge. This trend was not unique to Bulgaria but mirrored developments in other CEE countries, as discussed in Chapter 1. Between 1990 and 2020, the sector experienced rapid and steady growth, as illustrated in Figure 1. This growth was mainly driven by substantial foreign funding, which accounted for nearly three-quarters of the NGOs' revenue in the 1990s (Gorchilova 2010b, quoting MBMD 2003). Although the share of NGOs' income from domestic sources increased after 2000, external funding continued to be crucial for the survival and development of the sector (Smilova 2017, Meyer et al. 2020). This was especially true for organisations working in the field of human rights and advocacy (see Chapter 5).

Figure 1: Registered NGOs in Bulgaria, 1996 - 2017[51]



Source: Compiled by author from the Bulstat register

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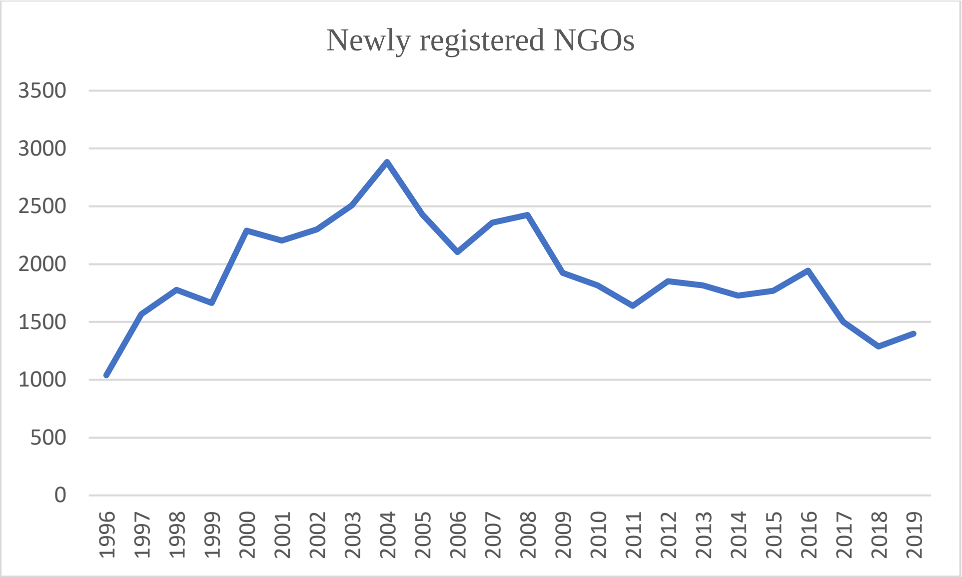
[51] Based on data from the Bulstat register, where all new NGOs were required to register between 1996 and 2018.

the number of active organisations, however, is significantly lower than the number of registered organisations as many organisations were only registered as a tool to access funding. Some organisations never started working or only had a single project. Based on data from the National Statistics Institute concerning organisations submitting financial reports (including zero reports), it has been estimated that between 20% and 23% of the registered organisations are active (Centre for the Study of Democracy 2010, Smilova 2017) or around 9,000 – 10,000 in 2017.

Although the sector continued to grow, the rate of new NGO registrations slowed down in the years leading up to Bulgaria's EU accession (Figure 2), mainly due to reduced foreign funding opportunities. With the speeding up of Bulgaria's accession negotiations, foreign donors began to gradually withdraw their support, interpreting the country's impending EU membership as an indicator of progress and a diminished reduced need for external assistance. Although new funding initiatives appeared, such as the Balkan Trust for Democracy (2003 – 2013), the Trust for Civil Society in Central and Eastern Europe (2001 – 2012), the Financial Mechanism of the European Economic Area (2008 – ongoing) and the America for Bulgaria Foundation (2009 – ongoing), the external funding opportunities for NGOs significantly decreased. The budgets of these newly established funding programmes have generally been insufficient to fill the gap left by withdrawal of the foreign donors and to satisfy the demand.

Figure 2: Number of new NGO registrations per year



Source: Compiled by author from data provided by the Bulstat register, request submitted under the Access to information Act

In parallel with the growth and development of NGOs, the legal framework for their functioning underwent significant transformation. The restrictive legislation inherited from the state-socialist era required comprehensive reform. The nature and quality of this legal transformation were crucial, as they would determine the future existence and functioning of the sector.

The right of Bulgarian citizens to form associations 'to satisfy and protect their interests' was officially restored with the adoption of new Constitution in 1991 (Article 44). However, the details and mechanisms for realising this right (for example, registration and termination procedures, governance, and reporting requirements), remained scantly regulated by the Persons and Family Act, inherited from state socialism. This Act was adopted in 1949 and amended in 1989 but was still considered 'outdated, as a meaning and a spirit' (Ianovski 2002:58). The lack of an adequate legal framework allowed NGOs to be used for illegal activities, such as 'money laundering'. This strongly damaged their image and created a unfavourable environment for their work and development.

A special law for NGOs – the Non-profit Legal Entities Act, regulating their establishment and functioning was only passed at the end of 2000 and came into force in January 2001. According to the Bulgarian Centre for Non-profit Law, the law gave ‘a relatively good legal framework, allowing for the establishment and normal functioning of non-profit organisations in Bulgaria’ (Panov et al. 2008:39). The contribution of the law for improving the quality of the legal environment for NGOs was recognised by the 2002 NGO Sustainability Index (USAID 2002), which gave Bulgaria significantly higher rating on this indicator, compared to the previous year. Although the legal environment has deteriorated slightly since then, mostly because of issues related to the implementation of the legislation[52], the country has consistently been among the top three CEE countries on this indicator[53] (USAID 2020).

The Non-profit Legal Entities Act granted NGOs the freedom to choose their goals and the methods to achieve them. Initially NGOs’ engagement with social, educational and health services was limited by other laws, preventing them from registering as providers (in the case of healthcare) or delivering services on behalf of the state (in the case of social and educational services). This changed in 2003 when the Social Services Act was amended, allowing private organisations and NGOs to provide social services as state-delegated activities. Restrictions related to healthcare and education were also removed, although much later, in 2015. At present, the only restriction on NGO’s goals

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[52] For example, related to the speed of the process or the bureaucracy.

[53] Overall, with the exception of Hungary, the EU member states from CEE have similar good scores on this indicator. It mainly assesses the impact of the NGO legal framework and the country’s tax policy on NGO registration and functioning, including legal opportunities to mobilise financial resources.

and areas of work concerns political activities, which are considered to be in the domain of political parties (Constitution of the Republic of Bulgaria Art.12.2).

Enabled by the removal of restrictions on their goals and activities, post-socialist NGOs became active in a wide range of new areas, such as social services and advocacy, alongside their traditional focus on culture and education. However, since the 2000s there has been a trend of declining involvement in policy advocacy activities and growing focus on social service provision. This shift was especially noticeable after the amendment of the Social Assistance Act, which allowed private organisations to deliver social services on behalf of the state. By the early 2010s, approximately 20% of social services were provided by NGOs (Bulgarian Centre for Non-profit Law 2014). At the same time, the number of NGOs participating in lobbying groups decreased by 40% between the end of the 1990s and the beginning of the 2000s, while those maintaining close links with such groups declined by 25% (MBMD 2002:47).

Despite the declining NGO engagement with policy campaigns, advocacy remains one of the highest ranked areas in the NGO sustainability index over the last couple of decades (USAID 2020). This positive assessment reflects the country's favourable legal and institutional framework, which allows NGOs to participate in the policymaking process as members of various permanent or ad-hoc structures. At the same time, it is a recognition of NGOs' capacity to form coalitions to pursue issues of common interest. Similarly, exploring the different dimensions of activism in CEE, Petrova and Tarrow (2007) find that the 'transactional activism' – a term they use to describe the relational aspect of activism, i.e., the interactions among organised non-state actors and between them and other actors – is robust. Indeed, there are numerous examples of successful

NGO coalitions and campaigns in the area of environmental protection, electoral process, civil society legislation, deinstitutionalisation of children (USAID 2020, Ivanova and Bogdanov 2013). Finally, some of the oldest, most experienced, well-established, and visible organisations in the country fall in this category (Smilova 2017:151).

While the focus of the present research is on organised non-state actors', it is important to note that the last decade saw many cases of spontaneous citizen mobilisation. The most prominent example is the 2013-2014 anti-government protests (Krastev 2013). Additionally, there have been numerous protests of environmentalists (WWF 2011 and 2016, Petkova 2018, Todorov 2020) and a successful campaign of mothers of disabled children (Stoyanova and Stoynova 2018). Although this type of mobilisation is important, is falls outside of the focus of the present research and therefore will not be included in the analysis.

Legal and institutional framework for participation in policymaking

The development of the legal and institutional framework for NGO participation in policymaking in Bulgaria lagged behind. Many CEE countries, including Estonia, Croatia, Hungary, Serbia, Slovakia, and Slovenia, sought to coordinate and facilitate NGO involvement by adopting strategic documents and/or establishing special bodies, as early as 1998 (Shabani et al. 2014). However, Bulgaria did not make targeted efforts to support NGO development or establish mechanisms for their interaction with public institutions until the beginning of 2010s (Council of Ministers of the Republic of Bulgaria 2012). While NGOs have been able to participate in policy- and decision-making as members of various permanent or temporary consultative bodies, the legal framework for this participation has been dispersed among various legal acts. In addition, the rules and procedures for consultations and selection of participants were often not clear enough, with some exceptions.

One of the first consultative bodies was in the area of disability – the National Council for Integration of Disabled People[54]. It was established with the 1995 Protection, Integration and Social Rehabilitation of Invalids Act as a consultative organ to the Council of Ministers, The Council for Integration of Disabled people included disability NGOs recognised by the state as ‘nationally representative’ – a term introduced by the law, linked to requirements concerning NGOs membership/clients and geographical coverage.

Another hinderance to NGO participation has been the absence of general requirement for state institutions to consult organisations. This meant that NGO involvement often depended on the goodwill of the relevant administration (Slavova 2008, Panov et al. 2008). Even though compulsory requirements were sometimes introduced for the administration to consult draft policies and legislation with the relevant bodies, such as the Council for Integration of People with Disabilities, the lack of sanctions for non-compliance led to non-implementation or merely formal implementation (see Chapter 5). Many of these problems, to various degrees, remain until today.

In 2012, after a broad consultative process with NGOs and support from a minister (Genchev et al. 2015), the Bulgarian government adopted the Strategy for Supporting the Development of Civil Society Organisations 2012 – 2015. The strategy aimed ‘to

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[54] Initially named the Council for Rehabilitation and Social Integration, it was renamed in 2005 to the National Council for Integration of People with Disabilities. Following the new Disabled People Act, which entered into force in 2019, the name was changed to the National Council for Disabled People.

create favourable conditions for development of civil society organisations and to stimulate partnership between them and the institutions at national and local level' (Council of Ministers of the Republic of Bulgaria 2012:3). Key measures in the strategy included creating a Council for Civil Society Development attached to the Council of Ministers, developing a funding mechanism for NGOs, and establishing clear rules and procedures for citizen participation.

However, the implementation of the strategy has been slow, partly due to the political instability within the country. This instability was characterised by social and political protests in 2013 and the turnover of four governments, including two caretaker governments, between 2013 and 2014. Another contributing factor was the lack of political will, as evidenced by the inadequate funding, unclear responsibilities, and the absence of a dedicated institution to oversee the strategy's implementations (Genchev et al. 2015). Furthermore, the government backtracked on core provisions, such as the establishment of Council for Civil Society Development and the NGO funding mechanism, which were removed from the proposed legislative changes. Although these provisions were eventually reinstated and adopted in 2016, their enforcement was postponed until 2018. As of 2021, the Council has still not started working, despite the election of its members in May 2020.

Despite the favourable legal environment, the rise of illiberal tendencies in Bulgarian society and politics over the past decade has created an unfavourable climate for NGO development. During the anti-government protests in the early 2010s, pro-government media targeted NGOs, labelling them 'foreign agents' and accusing them of being paid to participate in the protests (Smilova 2017, 2019)[55]. Similar tactics aimed to delegitimise NGOs were used in many CEE countries, where the anti-NGO narratives became a 'lingua franca' for authoritarian populist governments (Enyedi 2020). In Bulgaria, this anti-NGO rhetoric served the interest of the oligarchy, which controlled media ownership. Its aim was 'to discredit any public opposition' to its operation (Stanoeva 2017).

The rise of nationalism and conservatism led to an intensification of this rhetoric, especially after the entry of the far-right 'United patriots'[56] into the government in 2017. This change led to attacks against NGOs increasingly coming from high-ranked politicians, including vice-prime ministers, members of the parliament, and Bulgarian members of the European Parliament[57] (USAID 2020, 2019). The United Patriots have also been linked to the delayed initiation of the Council for Civil Society Development (Georgieva 2021, Dachkova 2020).

Illiberal and conservative citizen groups, which became more active and visible after 2017, have also strongly attacked NGOs. They view NGOs as private organisations promoting foreign interests and practices contrary to the traditional Bulgarian family values. Politicians have found this focus on traditional, Christian values convenient for diverting attention from economic and geopolitical issues (Kabakchieva 2020). Initially, human rights NGOs, especially those working on gender and minority rights, were the most affected. More recently, children's organisations and social service providers have

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[55] It should be noted that media freedom in Bulgaria has been deteriorating in the last decade. The country moved from 70th place (out of 178 countries) in 2010, to 100th in 2014 and 130th in 2020 (Reporters without Borders 2021).

[56] Consisting of three nationalist parties – Ataka (Attack), VMRO-BND (Internal Macedonian Revolutionary Organization – Bulgarian National Movement) and NFSB (National Front for the Salvation of Bulgaria).

[57] In 2019, one of the ruling parties even sent a letter to the Prosecutor General requesting the deregistration of the human rights organisation Bulgarian Helsinki Committee (Human Rights Watch 2019).

also come under attack.

These developments have significantly damaged the public image of NGOs (Belcheva et al. 2018) and hindered their work. Policies and legislation that NGOs advocated for and were actively involved in developing, such as the National Child Strategy 2019 – 2030 and the Social Services Act, were either withdrawn or their implementation was delayed due to the strong opposition from conservative and illiberal groups, disseminating fake news[58]. The negative public perception of NGOs has made it difficult for them ‘to reach out to citizens and to cooperate with public authorities in order to have a lasting impact on the social and legal environment’ (Smilova 2019:42). There have been instances where local authorities were reluctant to publicly their support for NGOs (USAID 2020). Some organisations fear that advocating for progressive reforms might be counterproductive in the current (USAID 2019).

Disability organisations

As part of the overall growth of the NGO sector, numerous organisations disability organisations were established. These can be provisionally put into five groups: traditional national-level membership-based organisations of disabled people, grass-root organisations of disabled people, organisations of parents of disabled children, human rights organisations, and organisations providing services for disabled people.

The traditional organisations of disabled people are national-level membership-based NGOs with structures throughout the country. As of 2019 there were nine such NGOs,

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[58] For example, those protesting against the National Child Strategy, were led to believe that the Strategy would make it easier for the state to take away their children, a misconception that fuelled opposition.

most established before 1990[59]. Like other organisations from the state socialist period[60], they had undergone 'successful process of reform and adaptations to new democratic conditions' (Ekiert and Foa, 2011: 6). The largest, the Union of Invalids, has more than 70,000 members and 350 structures nationwide, while one of the smallest, Little People of Bulgaria, has less than 200 members. Their main activities include providing specialised disability-specific information and services and organising arts, culture, sports, and tourism events to facilitate socialisation of their members. In addition, the unions of the deaf and blind continue sheltered employment on a much smaller scale, affected by economic liberalisation and the loss of certain preferences, such as tax deductions and public procurements access. The organisations from this group also participate in the policymaking as members of the National Council for Integration of People with Disabilities.

The emergence of grassroots organisations of disabled people and parents was spurred by Bulgaria's deteriorating economic situation and the limited and decreasing state support. Like similar organisations in other post-socialist countries (Fröhlich 2012) their focus is on self-help, with a strong emphasis on financial and material support, information, and specialised services. Like traditional NGOs, they often promote inclusion through special events and activities for their members or by establishing special services, rather than seeking opportunities for inclusion in mainstream settings and activities. Many of these organisations have ceased operation or become branches of larger organisations, mirroring developments in other areas, such as gender

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[59] This included the Union of the deaf, the Union of the blind, and the National Consumer Cooperative of the Blind, all of which survived the change of the regime. Also included were the Union of Invalids, established by a Politburo's decision, and the Union of War Invalids, which revived the Union of Invalid Associations dismantled in the 1959s.

[60] It has been estimated that around 4-5% of the active NGOs in Bulgaria were established before 1989 (Bulgarian Centre for Non-profit Law 2006, Kabakchieva and Kurzydloqski 2012).

(Ivancheva 2015). A few national-level parents' organisations were established in the 1990s, and joined the National Council for Integration of People with Disabilities.

Probably the largest group of organisations within the disability sector consists of social service providers (Stambolovo Municipality 2019). There has been a steady increase in the number of these organisations, following the 2023 amendments in the Social Assistance Act. Most of them have limited capacity and mainly work at the local level, delivering services on behalf of the state. However, there are also larger, well-established, and better-resourced organisations, capable of mobilising both domestic and external resources, and meeting the criteria for participation in the NCIPD. A key distinction between service providers and other groups, such as traditional, grassroots and parents' organisations, is that the former are usually organisations *for* disabled people, while the latter are organisations *of* disabled people (including parents, as a specific category). Service providers tend to be dominated by professionals, sometimes referred to as 'organisations of professionals', where disabled people 'remain objects of professional activity, target groups of projects that are being implemented' (Stambolovo Municipality 2019:33).

The final and smallest group is comprised of human rights NGOs. Thes organisations promote a social and human rights understanding of disability and aim to influence policies and legislation. They operate at the national level and engage in activities such as research, training, information, and awareness raising campaigns, strategic litigation, advocacy, and lobbying. At present, the main human rights organisations active in the disability area are the Centre for Independent Living – Sofia, an organisation of disabled people, and the Bulgarian Helsinki Committee, a general human rights organisation that also addresses issues related to institutionalisation and legal capacity. Both organisations were founded in the first years of the transition and have been active for more than 25 years. They have often joined forces to advocate for change, with the most recent example being their campaign to revise Bulgaria's deinstitutionalisation reform of adult services and the use of EU funds. This campaign was supported by European human rights organisations like the European Network on Independent Living and Validity (see Chapter 5).

Regarding opportunities for participation in the policymaking process, disability was among the first areas where a formal mechanism for consultations was establishes. The Council for Integration of People with Disabilities was created in 1996 as a consultative body for 'co-operation and interaction' in the disability area (Council of Ministers, 1996: Art. 2). Initially, it had 13 NGOs members, including traditional organisations, parents' organisations, and service providers recognised as nationally representative. Their number grew to 21 in 2019. The Council's formation and its work will be discussed in more details in Chapter 5.

Conclusion

The review of disability policies revealed that medicalised approaches and solutions, characteristic of state socialism, continue to dominate present day policies and practices. Institutions for disabled people, initially established as charitable initiatives after Bulgaria's liberation, became widespread during state socialism. This proliferation was influenced by the regime's strong productivist and medicalised understanding of disability. However, in the last two decades, new ideas and perspectives related to social inclusion, participation, and choice have gradually entered the country. This shift was further reinforced following the ratification of the Convention on the Rights of Persons with Disabilities, incorporating a disability rights perspective. As a result, new types of community-based support services have been developed, as alternatives to institutionalisation, which traditionally sought to remove people from the community. Still, the new services failed to adequately support disabled people's inclusion and participation in community.

Many of the new progressive ideas and practices in the area of disability, among others, were introduced to the country though NGOs. These organisations provided alternative community-based services, conducted awareness-raising campaigns, and engaged in policy advocacy. The lifting of state socialist restrictions led to the emergence of a large and diverse NGO sector, with many organisations active in the disability area. This sector benefits from a good legal framework and, despite challenges, especially in the last decade, has opportunities for participation in the policy process. Organisations of disabled people have had access to the policymaking process since as early as 1996 through the National Council for Integration of People with Disabilities. The disability sector, however, is dominated by organisations with traditional views, while NGOs advocating for disability rights are fewer and weaker. Overall, the growth and development of disability organisations and their involvement in the policymaking process have not led to a radical transformation of disability policies and practices.

Chapter 4: Domestic policy frames and EU policies

Looking to explain the limits of Bulgarian disability policy reforms in the context of EU accession, this chapter employs policy frame analysis to examine domestic policies, their development over time, and their relation to EU discourses and influences. It shows that the emergence of discourses at the EU level typically preceded their introduction and/or establishment nationally, indicating possible EU influence. This influence has manifested through various mechanisms, including soft pressure (for example, through initiatives and frameworks like the Open Method of Coordination and EU monitoring reports), funding (pre-accession funds and Structural Funds), socialisation, and lessons drawing (see Chapter 1).

The policy frame analysis is applied to a specific disability policy – assistance services. This case was chosen for three main reasons: the significance of the service for disabled people's inclusion; the EU's growing emphasis on assistance services, especially post-2010; and the substantial development of the service in Bulgaria in the past two decades. Assistance services are considered essential for the independence and social inclusion of disabled people by disability rights advocates (Europen Network on Independent Living 2013, Ratzka 2017 and 2004) and disability studies scholars (Barnes 2007, Stainton and Boyce 2004, Morris 2010, Mladenov 2012). The United Nations Convention on the Rights of Persons with Disabilities also emphasises the importance of personal assistance for enabling disabled people to participate in the community (Article 19). Furthermore, the EU has pledge to actively promote the access of disabled people to quality community-based services, including personal assistance. The European Disability Strategy 2010-2020 (European Commission 2010b:6) highlights the importance of personal assistance for achieving the overarching EU-level objective of full participation of disabled people in society and recommends the utilisation of European Structural and Investment Funds (ESIFs) for the development of personal assistance schemes. Finally, assistance services in Bulgaria have more than 15 years history, allowing for an analysis of the dynamics in policy frame development during the period of Bulgaria’s EU accession and membership.

The chapter begins with a description of the policy frame analysis method. It then, provides an overview of the development of assistance services in Bulgaria and goes on to identify the main policy frames and to explore their dynamics. This section is more descriptive, aiming to present different elements of the policy frames. The final part of the chapter contextualises the identified frames and tendencies, tracing the evolution of domestic and EU discourses and exploring potential EU influences.

Discursive approaches and policy frame analysis

The emergence of policy frame analysis is linked to the growing interest in the role of language and ideas in public policy (Durnova et al. 2016, Fischer et al 2015, Zittoun 2009) and the development of a large and relatively heterogenous group of approaches, often referred to as discursive (Peters and Zittoun 2016) or interpretative (Heinelt and Münch 2018). These approaches challenge the objective nature of the world and emphasise the role of discourses in constructing realities.

A central feature of many discursive approaches is the attention to problem definition as an integral part of the policymaking process, which enables certain policy choices while making other redundant (Heinelt and Münch 2018, Barbehön et al. 2015).

Different methods of policy analysis have been developed to study the discursive constructions of problems, one of which is frame analysis. The introduction of the concept of ‘frames’ to policy analysis is often associated with the work of Rein and Schön (1993:146) who view frames as ‘diagnostic/prescriptive stories that tell, within a given issue terrain, what needs fixing and how it might be fixed’ (Rein and Schön 1996:89). Different policy frames provide different interpretations of the problem and thus may lead to different policy solutions. For example, the social disadvantages faced by disabled people are regarded as caused by their physical impairments from the perspective of the ‘medical model’, while the same disadvantages are seen as caused by how society is organised, from a social model perspective (Oliver, 1990; 1996). Consequently, the hard ‘fact’ of impairment (e.g., being with one hand) is endowed with different meanings in the two cases, yielding different and sometimes even conflicting social policy responses – medical treatment and rehabilitation vs. person-centred support services; charity vs. empowerment, etc.

At certain times and places, there are hegemonic frames that shape our understanding of and responses to various issues. They impose constraints on thinking and acting by excluding alternative ways to think and act. Thus, certain issues may not be defined as problems and may not be included in the policy agenda. For example, disabled people’s exclusion only became recognised as a problem, and policies aimed to support participation began to be developed when the social and human rights discourses became stronger. This shift occurred thanks to the disabled people’s movement and the adoption of the UN Convention on the Rights of Persons with Disabilities.

Frames can also be used strategically by actors to advance specific interpretation of a situation or issue, thereby legitimising a certain set of policy solutions, or helping to mobilise consensus and action (Snow et al. 1986). For example, calls for direct payments for personal assistance have been argued as a way to create a market for services and enhance competition, aligning with the dominant neoliberal agenda (Mladenov 2015). Gender equality has been framed in terms of economic benefits to fit the EU's market-oriented agenda (Lombardo et al. 2009). However, some scholars question the effectiveness of such strategies in achieving the desired outcomes in terms of equality. Bacchi (2009:21) warns that framing women as a resource for the economy overlooks the issue of unpaid labour.

Frames can be studied as interpretations of a policy issue, containing a description of the problem (diagnostic element) and a strategy for its resolution (prognostic element). At the same time, frames have 'normative-prescriptive' implications (Dekker 2017) determining not only 'what counts as fact' but also 'how one makes the normative leap from facts to prescriptions for action' (Schön and Rein 1994:XVIII).

The method of policy frame analysis will be used here to explore (1) how the problem that assistance services seek to address is represented, (2) how it is justified (why it is a problem; what causes it), what specific solutions are proposed (cognitive element) and what were the assumptions and ways of thinking underpinning the problem description (normative element).

The concept of 'personal assistance' and the development of assistance services in Bulgaria

This research uses the definition of personal assistance provided by the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) in its General Comment No.5 on the right to live independently and being included in the community.

Personal assistance is described by the CRPD Committee as ‘person-directed/“user”-led human support available to a person with disability’ and ‘a tool for independent living’ (2017:16, d). Recognising the existence of different models of personal assistance, the Committee emphasises that for the service to support disabled people’s independence and full participation, it needs to be organised in a specific way. For example, funding should be allocated to and controlled by the disabled person, who should be able to choose whether to contract out the service or act as an employer, choosing their preferred degree of personal control. The disabled person should be central in decisions about the service and determine ‘by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers’ (2017:16, ii). The user of the service should be able to recruit, train, and supervise their assistants and should not be required to ‘share’ assistants with others (for example, when the assistant is expected to support more than one person).

Assistance services were introduced in Bulgaria at the beginning of the 2000s, when the country was already halfway into its accession negotiations with the EU and nearing the closure of the Chapter on Employment and Social Policy[61]. The table below presents all national level assistance programmes implemented during the period covered by the research, ordered chronologically. It illustrates the three ‘stages’ of development of assistance services in Bulgaria: (1) national programmes, prepared and funded by the government; (2) schemes within the framework of and co-funded by the European

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[61] The Chapter was provisionally closed in April 2002 and finally closed in December 2004.

Structural and Investment Funds, and (3) personal assistance law.

The foundations of the service were laid with the first national programmes. New approaches to organisation and provision were piloted with ESIFs funding, which facilitated the implementation of numerous, albeit short-term, assistance programmes. The programme-based provision of the service continued until the Personal Assistance Act came into force at the beginning of 2019.

Table 2: Assistance programmes implemented at the national level

Name of the programme/scheme[62]	**Period of implementation**[63]	**Funding**
First national assistance programmes		
National Programme 'From Social Benefits to Employment'	2002- (2002-2004)[64]	State budget
National Programme 'Assistants for Disabled People'	2005 – ongoing	State budget
Programmes within the framework of the European Structural and Investment Funds		
Care in a family environment for independence and dignity of people with different impairments and people living alone – activities 'Social Assistant' and 'Home helper' (BG 051POO1/07/5.2.01)	2007-2009	ESIFs with national co-financing
Development and improvement of the service 'Personal assistant' for people with different impairments and people living alone (BG051PO001/07/5.2.02)	2008-2009	ESIFs with national co-financing
Care in a family environment for independence and dignity of people with different impairments and people living alone – activities 'Social Assistant' and 'Home helper' – Phase 2 (BG051PO001-5.2.01)	2009-2010	ESIFs with national co-financing
Development and improvement of the service 'Personal assistant' for people with different	2010-2013	ESIFs with national co-

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[62] The titles of the schemes are translated from Bulgarian by the author.

[63] Covers the period from the announcement of the call for proposals until the end date for the implementation of the project, as specified in the call documentation. The service provision period is usually between 10 and 18 months.

[64] In 2022, the Programme was still being implemented; however, assistance services were taken out and formed into a distinct programme at the end of 2004.

Name of the programme/scheme[62]	**Period of implementation**[63]	**Funding**
impairments and people living alone – Phase 2 (BG051PO001/07/5.2.05)		financing
Care in a family environment for independence and dignity of people with different impairments and people living alone – activities 'Social Assistant' and 'Home helper' – Phase 3 (BG051PO001-5.2.07)	2010-2011	ESIFs with national co-financing
Alternatives (BG 051PO001-5.2.09)	2011-2015	ESIFs with national co-financing
size – Phase 2 (BG 051PO001-5.2.16)	2015	ESIFs with national co-financing
New Alternatives	03.2015-04.2016	ESIFs with national co-financing
Independent Living	2015-2016 2017, 2018, 2019	ESIFs with national co-financing (2015-2016); national budget (mid 2016-end of 2019)
Law		
Personal Assistance Act	01.12.2019 -	State budget

In addition to the programmes mentioned above, there were a few other assistance programmes, which are not included in the analysis due to their limited coverage. From April 2003 until the end of 2006, a pilot project titled Social Services Against New Employment (SANE) was implemented in collaboration between the Ministry of Labour and Social Policy and the United Nations Development Programme. This project started with 4 municipalities and although its territorial coverage gradually expanded, by 2006 it only covered 12 municipalities out of a total of 265. In 2007, the Sofia Municipality established another assistance scheme, but this was exclusively for disabled people residing within the municipality. Due to funding limitations, the scheme provides support to a limited number of people[65].

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[65] For an analysis of the Sofia Municipality 'Assistants for Independent Living' scheme, see Mladenov (2017).

Personal assistance policy frames

This section conducts a comprehensive review of key documents that detail various national-level assistance programmes and schemes, with the aim to identify and analyse the main policy frames. Although all frames propose assistance services as a solution, each frame focuses on different problems – for example, unemployment, social exclusion, quality of life – and different target groups, including disabled people, unemployed people, and carers. The variations in how problems are defined within these frames significantly influence the organisation and administration of assistance services. This analysis explores how these differences impact the degree of choice and control of disabled people and the potential of the services to support their full participation and inclusion in society.

The analysis demonstrates the evolution of the policy frames across the programmes. The initial national programmes were dominated by employment-related frames and a focus on carers, which remained a key element in assistance policies throughout the period covered by this research. Subsequently, within the ESIFs schemes, the emphasis shifted towards social inclusion frames that encompassed both disabled people and carers/family members, with employment being viewed as a mechanism for inclusion. Several subframes also emerge, including deinstitutionalisation (as an aspect of social inclusion), choice and control (reflecting a human rights perspective), and long-term care (indicating a medicalised perspective). Finally, the Personal Assistance Act and its justifications revealed a renewed focus on family members' employment, combined with a human rights policy frame.

First assistance programmes

- The first assistance services in Bulgaria were introduced as part of the National Programme ‘From social benefits to employment’ (Ministry of Labour and Social Policy, 2002a). The Programme was piloted in 11 municipalities from 1st of October to 31st of December 2002 and then scaled up to the national level. It provided two types of assistance services to eligible disabled adults and children, as well as older people: personal assistant (PA) and social assistant (SA). The former was restricted to employing family members as assistants, primarily providing in-home support, while the latter was more focused on supporting social activities. In 2005, these the two services were separated to form a new national programme – ‘Assistants to disabled people’, which is still in operation. These initial programmes served as a model for the development of subsequent assistance programmes.

National Programme ‘From social benefits to employment’ (NPSBE) – focus on activation and employment

The analysis primarily draws on the framework document of the National Programme ‘From social benefits to employment’. This document includes the programme’s justification, goals and objectives, eligibility criteria, activities, duration, responsible institutions, expected results, and the monitoring and evaluation framework. Drafted and officially adopted by the Ministry of Labour and Social Policy, which conducts annual revisions, the programme reflects the Ministry’s perspective. Other relevant documents, such as official reports and media publications, were also reviewed.

Four assistance frames have emerged over the years: (1) employment of working-age adults (with an emphasis on activation[66]), (2) employment of carers, (3) deinstitutionalisation, and (4) quality of life of disabled people. Table 3 below summarises the main characteristics of these frames, examining how they define the problem, its perceived causes, and their underlining values.

Table 3: Key frames in National Programme 'From social benefits to employment'

Frame	**Employment (activation, fighting unemployment)** (since 2002)	**Employment of working-age carers** (since 2003)	**De-institutionalisation** (since 2003)	**Quality of life of disabled people** (since 2004)
What is the problem?	High rates of working-age unemployment and high welfare costs.	Carers are unable to work and get enough qualifying years for pension.	Higher costs of institutional care compared to community living; 'unclear' effect of institutional care.	The daily needs of many disabled people with severe impairments are not adequately met.
What is the cause of the problem?	The provision of benefits leads to 'benefits dependency' and deepens people's 'social inadequacy' – people lose motivation to work and rely on benefits.	Relatives need to care for their disabled family members, which prevents them from taking up paid jobs. Benefits are a temporary solution.	N/A	Many people with severe disabilities (above 90% 'loss of ability to work') are not able to satisfy their needs without assistance.
What is the solution?	Transition from 'passive' to 'active' labour market measures – creating subsidised employment (including in	Provision of a PA service where working-age carers who fulfil certain conditions can be employed as PAs of their	Assistance services (mostly SA) where care and support are provided to disabled people in the family	SA service where assistants provide care and support to disabled people with

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[66] Eurostat (2018) defines activation policies as 'policies designed to encourage unemployed to step up their job search after an initial spell of unemployment, by making receipt of benefit conditional on participation in programmes'.

Frame	**Employment (activation, fighting unemployment)** (since 2002)	**Employment of working-age carers** (since 2003)	**De-institutionalisation** (since 2003)	**Quality of life of disabled people** (since 2004)
	assistance services) and providing education and training to improve individuals' competitiveness and build their motivation.	disabled family members.	('family-based care').	their daily needs.
What are the underpinning principles?	Reducing welfare costs; increasing self-sufficiency (self-reliance); workforce development ('activation').	Reducing welfare costs; increasing self-sufficiency (self-reliance).	Reducing welfare costs.	Satisfying basic needs.

Employment of working-age adults was the main frame during the pilot phase (October – December 2002) of the National Programme 'From Social Benefits to Employment'. It sought to address growing unemployment rates and high benefits expenditures. The source of the problems was identified as the benefits system itself, which allegedly made recipients passive, leading to 'welfare dependency' or encouraging fraud. The benefits were seen as creating more problems than solutions, deepening recipients' 'social inadequacy' (Ministry of Labour and Social Policy 2002a:1). This negative attitude towards social assistance, prevalent during state socialism, persisted and even intensified during the transition period, with the notion of 'welfare dependency' becoming integrated into social policy thinking (Mladenov 2015:450).

The proposed solutions focused on (1) securing employment through subsidised placements and training, and (2) reducing expenditures through benefits conditionality. This approach is typical of 'active labour market' policies, which condition benefits receipt on participation in employment or training programmes The Programme's main target group, working-age unemployed people receiving benefits, were required to accept paid placement (subsidised employment) in community work, including social services, building, refurbishing, cleaning, horticultural work or other activities aimed to 'improve the work of the municipalities and the living environment' (Ministry of Labour and Social Policy 2002:5). When necessary, they could also take part in literacy or vocational training courses to improve their qualifications and skills. Those who refused to participate in the Programme for non-health-related reasons were sanctioned by having their benefits stopped (Republic of Bulgaria, Chamber of Audit 2004).

In 2003, two new frames appeared: employment of working-age carers, and deinstitutionalisation. While the former retained the focus on employment, it presented a somehow different perspective on the underlying cause of the problem. Carers were considered unable to pursue paid employment due to factors outside of their control – they 'do not work because of their dependency, which is caused by the need to provide constant care to their family members' (Ministry of Labour and Social Policy 2003a:2). Nonetheless, benefits were still seen as an inadequate solution, which, among other things, failed to allow carers to accumulate sufficient qualifying years for pension. The proposed solution was to employ working-age carers as PAs to their disabled family members. This approach was expected to address both the financial difficulties of families with disabled members, and the programme's specific goals, such as reducing benefits expenditures, transitioning from passive to active measures, and securing employment.

The deinstitutionalisation (DI) frame highlighted the high number of disabled people living in institutions as a main problem. Institutionalisation was criticised for its much higher costs for the state, compared to community living, aligning with the programme's efficiency concerns. This economic argument contrasted with the disability rights discourse, which criticises institutionalisation from a human rights perspective (Parker et al. 2016, CRPD Committee 2018).

In 2004, with the emergence of the quality of life frame, assistance services were discussed for the first time in relation to the benefits for disabled people. The goal of the social assistant service was improving the quality of life of disabled and severely ill people who live alone and whose self-care is difficult. Providing them with the help needed to satisfy their daily needs of constant care and structuring their free time. Ensuring social contacts while fully respecting their dignity' (Ministry of Labour and Social Policy 2003a:19). However, this frame remained marginal and did not significantly influence the service organisation and provision or the selection of assistants, where unemployment status remained the primary eligibility criteria.

Overall, while new frames emerged over the years, the themes of employment and cost-cutting continued to dominate. The programme aimed to 'create jobs', 'secure employment', 'reduce spending on benefits', 'increase social security system revenues', encourage 'active behaviour on the labour market', 'build sustainable work habits', and 'motivate the programme's target groups'. The stress on employment is not surprising, considering the programme was introduced as a key element of Bulgaria's active labour market policy and was included in the National Plans for Actions on Employment (see section Exploring EU's influence for context). Policy documents and the media consistently portrayed it as aimed at addressing unemployment by helping re-integrate long-term unemployed people (Ministry of Labour and Social Policy 2003b, Shuleva, quoted in Dnevnik 2002). Institutionally, the programme remains under the Employment Agency, an executive agency of the Minister of Labour and Social Policy, tasked with implementing the government's employment promotion policies.

The main disability-related frame, quality-of-life, was subordinated to employment concerns. Only working-age, long-term unemployed people receiving monthly unemployment benefits were eligible to work as assistants. A limited number of long-term unemployed not receiving benefits could also qualify, but only if they had a medical background. This requirement was based on the assumption that disabled people primarily required expert medical care. The marginal place of disability issues is also evident in the lack of references to the programme's relevance for disabled people in key policy documents about social inclusion and disability. Notable examples include the 2003 Strategy for Equal Opportunities of Disabled People and the 2003 National Strategy for Combating Poverty and Social Exclusion.

National Programme 'Assistants for Disabled People': a shift from market to disability concerns and social inclusion

While the National Programme 'Assistants for Disabled People' shared many similarities with its predecessor, it also introduced some important differences. First, the two employment-related frames from 'From Social Benefits to Employment' were replaced by a more general frame – employment of working-age unemployed people – focusing on addressing unemployment and reducing benefit spending by replacing passive measures with active ones. Second, the emphasis on employment frames was downplayed, emphasising instead the Programme's support for disabled people. This shift from labour market measures to disability concerns is evidenced by the programme's revised title ('Assistants to Disabled People', instead of 'From Social Benefits to Employment). In addition, the justification section became more focused on disabled people and in 2006 the wording of the programme's overall goal was revised to emphasise disability support as a primary concern (see table 4 below).

Table 4: Evolution of the main goal of National Programme 'Assistants for Disabled People'

2005	**2006 until 2019**
Securing employment to unemployed people as personal and social assistants and provision of family-based care to disabled or seriously ill people who live alone.	Providing family-based care to people with disabilities or seriously ill people by securing employment to unemployed people as personal and social assistants.

Third, a few years after the start of the programme, the framing of assistance as benefiting disabled people was strengthened by introducing a new frame – social inclusion – and transforming the deinstitutionalisation frame. Until 2010, the main frame concerning disabled people was 'quality of life', largely copy-pasted from the previous programme. Social inclusion and deinstitutionalisation were also present but limited to a couple of general references in the goals of the programme. It was only in 2011 that the programme acknowledged the isolation and exclusion of disabled people from society as a problem. It was attributed to the lack of adequate social inclusion services, among other things (Ministry of Labour and Social Policy 2011:1). At the same time, a cause-effect link was established between the lack of community services and the prevalence of institutional care, and between institutionalisation and social exclusion. Thus, deinstitutionalisation, previously linked to costs savings, became associated with social inclusion. This shift was influenced by strong domestic and international pressure on the country for deinstitutionalisation (coming from NGOs and the EU), where institutionalisation was framed as a social inclusion and human rights issue (see section 'Exploring EU's influence' in this chapter and Chapter 5).

Despite the strengthened focus on disabled people's quality of life and (since 2011) on social inclusion, the programme remained primarily concerned with increasing employment. 'To provide employment to unemployed people' was a main goal for both the PA and SA components. The expected results also emphasised the programme's contribution to 'improving employability', 'securing employment', 'acquiring social security rights', 'reducing funds spent on monthly benefits', and 'increasing the income in the social security system'. The annual reports about the implementation of the programme, prepared by the Agency for Social Assistance and the Employment Agency, did not provide information about the service users (such as the number of disabled people using assistance, or the number of people who have left institutions), but only covered the number of people employed as assistants.

There were no major changes in the content of the programme, including eligibility criteria and the organisation of the service, suggesting that the increased focus on disabled people was only rhetorical – a strategic framing used by the government to demonstrate its attention to the problems faced by disabled people. Thus, unemployment continued to be the main criterion determining the eligibility of assistants. Moreover, the programme remained in the portfolio of the Employment Agency, even though programmes concerned with social service provision, such as the Assistants for Disabled People, were usually administered by the Agency for Social Assistance. This

Agency is also part of the Ministry of Labour and Social Policy, responsible for implementing the government's policy on social assistance.

The programme also continued to be dominated by a medical understanding of disability. For example, social inclusion was defined as 'achieving social adaptability within the frame of the existing invalidity', rather than as full participation in society. At the same time, the organisation of the service restricted the flexibility in its provision. The working hours for assistants were set by the programme and the service providers. In addition, the social assistance was limited to 20 hours per week (Monday to Friday) for people with complex needs, and 10 hours per week for those transitioning out of institutional care. This arrangement not only restricted disabled people's choice and control but also meant that adequate support to ensure their participation in society was not provided.

Schemes co-funded by the European Structural and Investment Funds (ESIFs) and the Bulgarian Government

The European Structural and Investment Funds are an instrument of the European Union's regional policy and a key source of funding for social sector measures. They are allocated through multi-year programmes (operational programmes) that cover a seven-year programming period. these operational programmes developed by the member states in accordance with the ESIFs' regulations. They need to be approved by the European Commission for implementation.

This section examines how assistance is framed within schemes co-financed by the ESIFs and the Bulgarian government for the 2007-2013 and 2014-2020 programming periods. The analysis draws primarily on guidelines for applicants' and the application forms. The guidelines detail the justification, goals and implementation rules of the schemes, while the forms contain monitoring the implementation indicators. Throughout the period covered by the research, nine assistance schemes were implemented under the Human Resource Development Operational Programme.

In contrast to the initial national assistance programmes where employment frames dominated, the ESIF-funded schemes placed a stronger emphasis on social inclusion and quality of life of disabled people and their families. These two principal frames were present across all schemes, although better elaborated in the first two. In addition, four subframes were identified in some of the schemes: deinstitutionalisation, long-term integrated care, choice and control, and quality and effectiveness of the assistance provided. The table below provides an overview of the presence of these policy frames throughout the Human Resource Development Operational Programme.

Table 5: Main frames and subframes

Programming period **Frames**	**2007 – 2013**	**2014-2020** (end of 2017[67])
Social inclusion of families (through employment)	▨	▨ 2014
Social inclusion and quality of life of disabled people	▨	▨
- *Deinstitutionalisation*	▨	
- *Long-term and integrated care*		▨
- *Choice and control (human rights rhetoric)*	▨ 2011	▨
- *Quality and effectiveness of*	▨	

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[67] The last EU-funded assistance scheme in the 2014-2020 programming period ran until the end of 2017.

assistance (institutional framework)		

Despite the focus on inclusion, the schemes remained closely linked to employment issues. Unlike the initial national assistance programmes, where employment was a goal on its own right, these schemes viewed employment as a tool to facilitate the social inclusion of family members. The primary cause of social exclusion of carers, particularly women, was identified as their caring responsibilities, often leading to withdrawal from work and isolation from society (Table 5). Assistance services aimed to address this issue 'by providing an alternative choice for active participation in the real labour market' (Agency for Social Assistance 2007:20), encouraging family members to explore opportunities outside of subsidised employment schemes. Seeking to distinguish itself from the purely employment orientation of the initial national assistance programmes, one scheme explicitly stated that '[t]he goals of the scheme are not focused on securing employment of relatives of disabled people but on overcoming the social isolation of families with members who are dependent on constant care' (Agency for Social Assistance 2008:19).

Similar to the first national assistance programmes, the schemes funded by the ESIFs also prioritised the employment of relatives, while disability issues remained subordinated to employment considerations. Although they did not initially require assistants to be unemployed or of working age, priority was given to disabled people whose relatives were seeking to return to employment (Agency for Social Assistance 2008:19). Subsequently, this requirement was removed, but the preference for assistants to be working-aged was reinstated.

In the schemes offering social assistance services, employment was also viewed as an instrument for the social inclusion and participation of disabled people. One of the main goals of the SA schemes was ‘creating conditions for the effective exercise of their [disabled people’s] right to social inclusion, including through the effective exercise of their right to work and reducing the risk of institutional care’ (Agency for Social Assistance 2007:20).

Table 6: Main frames related to provision of assistance services

Frames	**Social inclusion and quality of life of disabled people**	**Social inclusion and quality of life of families (employment)**
What is the problem?	Disabled people are increasingly isolated from society and their daily needs are not adequately met. They cannot go to work.	Family members (with a focus on the mothers of disabled children) are at a higher risk of exclusion and poverty.
What is its cause?	Disabled people are unable to meet their needs, they are ‘dependent on constant care’. The support available in the community and tailored to disabled people’s individual needs is limited.	The care for a disabled child/person hinders family members’ access to employment, leading to a loss of income and isolation at home.
What is the solution	Assistance services: (1) social assistant, supporting people’s social activity; (2) home helper, assisting with daily tasks, such as cleaning, shopping, cooking; and (3) personal assistant.	Assistance services, allowing women to have ‘an alternative choice for professional realisation’. The increased income from employment will also improve the quality of life of the family.
What are the underlying principles?	Social inclusion (including through employment); community-living; care (satisfying basic needs).	Social inclusion (through employment); satisfying basic needs; participation in the open labour market.

The deinstitutionalisation subframe was present in all schemes during the 2007-2013 programming period. These schemes typically included the following objective: ‘reducing disabled people’s dependency on institutional care’, and many also featured corresponding result indicators, such as the number of people who have left institutions or whose institutionalisation has been prevented. The description of the causes for institutionalisation included a mix of social (lack of services) and medical model arguments (‘health related limitations’) (Agency for Social Assistance 2007:19) reflecting a superficial social understanding of disability. As a result, while some progressive changes were introduced in the organisation of the service, such as removing hourly limits, it remained inadequate for supporting people to leave institutions. The deinstitutionalisation subframe is absent from the 2013-2020 programming period, which is puzzling, given the growing emphasis and importance of deinstitutionalisation, especially in the context of the ESIFs.

In the 2014-2020 period, a long-term and integrated care subframe emerged, merging disabled and older people in one group, with a focus on those above 65. This frame offered a medicalised perspective towards social exclusion and poor quality of life, linking them to chronic illness and other health problems. The aging the population was cited as a reason for urgent actions. The emphasis on health issues led to an increased emphasis on health services. The proposed solution involved the provision of integrated health, social and other services, including assistance services, at newly established Centres for Hourly Provision of Services. These centres were modelled on the state socialist ‘home patronage’ (see Chapter 3).

The choice and control subframe, although present from the start of the operational programmes, gained prominence in 2011-2012 with Alternatives. This scheme aimed to ‘create opportunities for the disabled person to choose their assistant and decide how to organise the time for using the service’ (Agency for Social Assistance 2010:5). It sought to achieve this by introducing ‘individual budgets’ as a funding model. In the second programming period, the Independent Living scheme (2015-2019) further emphasised the importance of ensuring that disabled people can choose ‘the desired and needed assistant’ as a way to gain ‘confidence to control the environment’ (Ministry of Labour and Social Policy 2015:5).

The understanding of ‘choice and control’ in assistance programmes, however, only partially aligned with the approach promoted by the CRPD. For example, the term ‘individual budget’ referred merely to the number of hours, rather than funds, allocated to and controlled by the users. In addition, despite the stress on allowing disabled people to choose their assistants, their choices were confined to the pool of assistants offered by the provider. The preference for working-aged assistants further restricted their options. Thus, while disabled people were offered a certain degree of choice and control, it was quite limited.

A final subframe, present in some schemes between 2008 and 2013, is quality and effectiveness of assistance. This can be viewed as a ‘technical’ frame, focusing on issues related to the institutional framework for managing and delivering the service, directly impacting NGOs; role as service providers (see the next chapter). Initially, concerns related to the quality of the service led to its centralisation under the Agency for Social Assistance, portrayed as better resourced and trusted than NGOs and private providers. Preference was thus given to procedures for ‘direct provision’, where the Agency was the only eligible applicant, over open calls for proposals with competing applicants. At the end of the first programming period, this approach was recognised as problematic, leading to municipalities becoming involved in the provision of the service as partners of the Agency. In the second programming period, with the

Independent Living scheme, the service was completely decentralised to municipalities. However, although NGOs and private providers were allowed to participate as partners, their actual involvement was restricted by conditions related to their financial and human resources (for example, the ability to cover at least 20% of their expected project funding and to have staff on payroll) and the requirement for municipalities to deliver the service rather than act as intermediaries.

The Personal Assistance Act

The Personal Assistance Act was adopted following a campaign by mothers of disabled children, which took place from June to November 2018. The mothers took to the streets demanding legal regulation and dedicated public funding for personal assistance, to ensure their children can use the service[68]. The campaign attracted significant media interest, sparking a debate about the need for reforms (Stoyanova and Stoynova 2018). It was also supported, although not from the start, by the Ombudsman Maya Manolova, a member of an opposition party[69], who helped draft the Personal Assistance Act and its justification. The law was adopted, with amendments, in December 2018 and entered into force in January 2019.

Like previous assistance programmes, the law addresses both disabled people and their family members. For family members, the main frame is quality of life, attributing poverty and poor quality of life to a lack of income and social security. The insufficient income forces parents to use their child's disability benefits for the 'physical survival of the family' (Ombudsman of Republic of Bulgaria 2018: 2). Unlike previous assistance programmes,

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[68] With the ESIF-funded schemes, access to assistance services was contingent on the availability of project funding in the municipality. There were also frequent interruptions due to gaps between the different projects.

[69] At that time, a coalition led by GERB was governing the country, and the Ombudsman was from the Bulgarian Socialist Party.

which either secured employment for family members as assistants or encouraged them to seek employment on the open labour market, the law allows for both options.

With regard to disabled people, the law adopts a human rights perspective, framing assistance as a tool to facilitate the realisation of disabled people’s fundamental rights, ‘to be able to choose, to live independently, to be actively involved in society and to access services and activities’ (Article 2). The law’s justification draws extensively on Article 19 of the CRPD on independent living and community inclusion, as well as on the CRPD Committee’s General Comment on Article 19. In line with the Convention, independent living is defined as ‘the opportunity for a person with a disability to make autonomous decisions about their life and to implement them, with the necessary support’. This more general human rights frame, visible in both the law’s justification and its provisions, contains elements of choice and control and social inclusion frames. However, several aspects, such as the low hourly rate, the cap on the number of assistance hours, and the requirement for users to waive certain benefits (like the monthly allowances for raising a disabled child and the allowance for attendant services) make choosing assistants outside the family less appealing. This effectively reduces the service to a ‘cash benefit for the care giver’ (Mladenov 2022) and de facto limits disabled people’s choice of assistance.

Exploring the EU’s influence

This section places the policy frames identified in the analysis of assistance policies within a wider domestic and EU context. It examines the links between domestic developments – such as the emphasis on activation and the shift towards inclusion – and EU policies and approaches. Additionally, it explores EU’s interpretation of key concepts, like long-term care, and the potential implications on policy solutions in the field of disability.

Employment and activation (National Programme 'From Social Benefits to Employment')

- Assistance services were initially part of the government's New Social Policy Strategy, which aimed to transform the welfare philosophy and model from passive protection to active social policy. As a result, the employment and activation frame dominated the first assistance programme, From Social Benefits to Employment. Policymakers sought to tackle unemployment by creating jobs, 'transforming benefits expenditures in expenditures for salaries' (Republic of Bulgaria, Chamber of Audit, 2004:2), and enhancing unemployed people's skills and motivation for work. In the transition period, many CEE countries adopted similar policies 'out of necessity to be seen as legitimate competitors in global trade in progress to joining the EU' (Gould and Harris, 2012: n.p.).

The programme's focus on activation was aligned with the priorities of the European Employment Strategy's (EES). According to Sanz de Miguel (2016), the EES contains two dominant policy frames related to activation – 'disincentives' and 'knowledge economy'. The former identifies the welfare state's safety nets as a main cause of unemployment, fostering welfare dependency, and focuses on the individual characteristics of the unemployed, like lack of motivation and ability to adapt to work demands. The latter conceptualises unemployment as 'lack of employability' and highlights the importance of improving people's skills. Elements of both can be found in the dominant employment (activation) frame of the National Programme 'From Social Benefits to Employment'. In addition, the programme's framework document explicitly highlights its convergence with EU activation policies, which seek ‘to encourage unemployed and inactive people to accept employment, to improve their skills and to restore their work habits, with the aim to improve their employability’ (Ministry of Labour and Social Policy 2003a:1).

the EU was not the only external actor influencing Bulgaria’s policies during the transition. Immediately following the end of the state-socialist rule in the country, the EU ‘was not yet ready to consider a potential enlargement and its requirements’ and had ‘left the steering role in the transformation of the eastern countries to the monetarist supranational agencies’ (Ferge and Juhász, 2004:234). The International Monetary Fund and the World Bank, as the key ‘official creditors’ of Bulgaria in the post-1989 period, had an important influence on both economic and social policies across all CEE countries. They promoted ‘strengthening of individual responsibility and the weakening of public responsibility in social matters; […] privatization and marketization in all spheres; […] targeted assistance to the truly needy; the scaling-down of social insurance to strengthen private insurance and to decrease public spending; and the abolition of universal benefits as wasteful’ (Ferge and Juhász, 2004:234). The World Bank, for example, was concerned about the surging costs of the social protection system in Bulgaria. It promoted reforms aimed at ‘proper targeting and delivery of unemployment benefits’ (The World Bank 1991: para 47), limiting the duration of the unemployment benefits and the implementation of a ‘broad array of active labour market programmes’, such as counselling, retraining, and labour market information services (The World Bank 1996: para 20).

However, after the 1993 Copenhagen European Council, where the right of the CEE countries to join the EU was recognised, the EU's influence began to grow. This was particularly evident after the entry into force of the Europe Agreement in1995 and the publication of the 1997 EC Opinion on the Readiness of the Applicants to Join the Union. Preparing for EU membership became a main priority for the country, which sought to align all legislative and policy changes with the EU acquis. In areas with 'thin' acquis, such as social policy, alignment was sought with the EU's non-binding policies and requirements. For example, in its request for financial support from the IMF, the Government of Bulgaria (2002: para 17) stated that the country had 'taken steps to increase labour market flexibility' and that '[t]he amendments are consistent with EU and ILO standards'. Around that time, in the second half of 1990s, the European Union 'adopted activation as a corner stone of social policy development' (Lødemel and Trickey, 2001:14) and actively started promoting it.

The European Employment Strategy along with the European Commission's regular monitoring reports for accession countries were key instrument in this process. They put soft pressure on the countries to develop active labour policies. Thus, the Commission's reports on Bulgaria from the early 2000s (before the adoption of the National programme 'From Social Benefits to Employment') stressed the 'essential' role of active policies, which aimed to ensure 'that labour resources are made available to economically viable sectors to avoid high unemployment turning into a long-term liability for the public budget' (European Commission 2000d:27). The reports criticised the continued focus on passive measures by the Employment Agency (then known as National Employment Service) and the modest scope of active labour market measures (European Commission 2001b and 2002b). Although the Commission assessed positively the adoption of the National Programme 'From Social Benefits to

Employment', it continued to push for 'a stronger and more efficient activation approach' and a better targeting of active labour measures (European Commission 2003c:76). The need for reform, particularly in encouraging active job search and training, was also emphasised in the 2002 Joint Assessment of Bulgaria's Employment Priorities, which aimed to prepare the country for implementing the Employment Strategy and joining the EU[70].

Going back to the situation in Bulgaria, the country made its first steps towards active employment policies at the beginning of the 1990s. This included measures such as providing information and assistance in finding employment, temporary and partial wage subsidies for some newly employed people (including disabled and young people), promoting self-employment, and later, job creation programmes for temporary employment (Council of Ministers, 1991; The World Bank 1995). However, passive policies like benefits and early retirement continued to dominate employment and social policies in the 1990s (Terziev 2016:49, Sotiropoulos et al. 2003:668). It was not until the early 2000s, that Bulgaria changed its overall strategy on employment and social policy, moving from passive to active measures and from isolated measures and programmes to comprehensive national action plans on employment (Terziev 2016:50). With the adoption of a New Social Policy Strategy at the end of 2002, 'for the first time the State engaged fully in funding active labour market policies through the national budget' (Ministry of Labour and Social Policy 2002 n.p.). Active labour policy funds increased from 0.27% of the Gross Domestic Product in 2002 to 0.88% in 2003.

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[70] The work on the Joint Assessment began in 2000 and the document was signed by Bulgaria and the EU in October 2002. It was part of an Employment Policy Review examining the progress made by the country in aligning its employment system with the requirements of the European Employment Strategy.

The policy shift towards active measures came at a time when the country was experiencing a significant rise in unemployment levels – reaching nearly 20% in 2000, the highest in the region. Employment levels were also well below the EU average (Eurostat, LFSQ_ERGAN). This was a cause of concern for politicians, not only due to the huge economic and social costs of high unemployment for individuals and the economy, but also because it hindered Bulgaria's progress towards the employment-related goals of the Lisbon strategy, becoming 'a significant social problem for the successful integration in the EU' (Terziev 2016:28 and 30). Lendvai (2007) observed that the lower-than-average employment rates in accession countries put employment at the centre of public policies. Thus, the transition from passive policies, aimed to address the social problems caused by the economic and structural reforms, towards active policies seeking to reduce the number of unemployed and increase employment levels was closely linked to Bulgaria's accession policy (Terziev 2016). The inclusion of assistance services, or rather 'care services' as they did not seek to support disabled people's participation, in the National Programme, seemed logical. Carers often fit the profile of the Programme's target groups being working-age people, not in employment, and in receipt of social benefits.

A shift from market to disability concerns and social inclusion? (National Programme 'Assistants for Disabled People')

The increased focus of the National Programme 'Assistants for Disabled People' on the problems faced by disabled people, at least in terms of discourse, reflected growing interests in disability issues at the EU level. This interest led to designating 2003 as the European Year of People with Disabilities, and the adoption of a European Action Plan for equal opportunities of people with disabilities, in 2004, promoting access to quality support and services (see Chapter 2). In a context of continuing accession negotiations, Bulgaria sought to demonstrate its alignment with EU policies. This effort included adopting a National Strategy for Equal Opportunities of People with Disabilities and reinforcing the disability focus of assistance services. The establishment of a dedicated assistance programme for disabled people (National Programme ‘Assistants for Disabled People’) was presented in Bulgaria’s contribution to the 2005 EU monitoring report as a step towards enabling more disabled people to use support services and integrate into society (Government of Republic of Bulgaria 2006). At the same time, the programme remained primarily oriented towards securing employment, reflecting the continued emphasis on employment in EU social policy.

Social inclusion (ESIF-funded schemes)

With the start of the ESIF-funded programmes in 2007, social inclusion became the dominant assistance frame, marking a radical departure from the initial National Programme’s emphasis on activation and employment. The concept of social inclusion was new to Bulgaria and was actively promoted by the EU through various instruments, including recommendations in the EC monitoring reports (relevant during the accession period), the Open Method of Coordination, and the ESIFs.

Introduced at the Lisbon Summit in 2000 ‘as the means of spreading best practice and achieving greater convergence towards the main EU goals’ (European Council 2000c: Para 37), the OMC became a key policy instrument in the social area, covering social protection and social inclusion (Social OMC), long-term care, and pensions. During 2003-2004, preparing to join the OMC, Bulgaria adopted its first Strategy and Action Plan to Combat Poverty and Social Exclusion, making social inclusion ‘a government policy priority' (Republic of Bulgaria and the European Commission 2005:46). In 2005, the country signed a Joint Social Inclusion Memorandum with the EU and, at the end of 2006, adopted its first National Action Plan for Social Inclusion, officially joining the OMC and aligning with the EU common objectives against poverty and social exclusion. The Joint Social Inclusion Memorandum and the National Action Plan were among the key national documents that informed the development of the Human Resource Development Operational Programme (Ministry of Labour and Social Policy 2007), Within which the assistance services were implemented.

The Commission also put pressure on Bulgaria to implement social inclusion policies through its regular monitoring reports. While acknowledging Bulgaria's progress in adopting social inclusion policies, the EC urged the country to improve their implementation and monitoring (European Commission 2004:87). With the approaching accession, the pressure intensified. The Commission (2005c:51) warned that '[u]nless significant additional efforts are made in the field of social inclusion and public health, there is a serious risk that Bulgaria will not have effectively functioning systems in place by the date of accession.'

The social inclusion of disabled people, often considered among the most vulnerable, was a key area where the OMC urged countries to develop priority policies (Council of the European Union 2000b). These policies, in line with the OMC's objectives, were expected to facilitate participation in employment, access to resources, goods and services, and to prevent the risk of exclusion. In its final monitoring report before Bulgaria's EU accession, the Commission emphasised the importance of developing community services to facilitate disabled people's inclusion: the 'promotion of quality services for disabled persons, i.e. creation of community-based alternative services as well as increased access to employment and education, now needs to become a clear priority' (European Commission 2006b:40).

Finally, social inclusion was also promoted through the ESIFs, particularly, the European Social Fund (ESF), which was a main source of funding for assistance programmes. A key task of the ESF was to support policies, aligned with the EC's objectives for social inclusion, 'especially that of disadvantaged groups, such as disabled people' (European Parliament 2006: Art.2(1)). Consequently, ESF's financial assistance prioritised actions aimed to reinforce the social inclusion of these groups, among others.

Social inclusion though employment

In the ESIF-funded assistance schemes, the social inclusion frames were strongly linked to employment, especially for family members. This framing reflects the ESF's strong emphasis on employment as a pathway to inclusion. Member states had to align their measures with the ESF's priorities to access its resources, which inevitably had impact on the framing and the specific measures.

The European Social Fund, as the 'Europe's main tool for promoting employment and social inclusion', played 'a very important role in re-coupling social policy and employment policy' (Lendvai 2007:33). In line with the EU's view of exclusion as persistent poverty (Daly 2006), ESF promoted 'inclusion into the labour market as the best way to integrate individuals into society and combat social exclusion' (ICF International, 2016:5). Thus, one of its priorities for 2007-2014 was 'reinforcing the social inclusion of disadvantaged people' by promoting 'pathways to integration and re-entry into employment for disadvantaged people' (European Parliament 2006: Art.3(1)(c)(i)), particularly targeting 'disabled people and people providing care for dependent family members'[71]. Assistance services, which targeted the same groups, fit well with the ESF's approach, which advocated for the provision of 'relevant support, community and care services' (Art.3(1)(c)(i) to facilitate integration into the labour market. The emphasis on employment was strengthened in the 2014-2020 programming period, as social inclusion became 'active inclusion' and participation became 'active participation' (European Parliament 2013, Art3(b)(i).

Together with this, the ESF regulations (European Parliament 2006 Art.3(1)(a)(ii)) encouraged member states to introduce 'measures to reconcile work and private life, such as access to childcare and care for dependent persons' in order to enhance the access of carers to employment and inclusion in the labour market. This emphasis can explain the shift in the ESIF-funded schemes from subsidised employment towards services allowing carers to seek jobs in the open labour market, and from framing assistance as a means of securing employment towards one of supporting inclusion through employment.

Long-term care and integrated care subframe

The framing of domestic assistance services in terms of long-term and integrated care, which appeared in the second programming period of the ESIFs, was part of Bulgaria's policy shift. This shift involved framing support services for disabled and older people

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[71] Alongside early school leavers and minorities.

as long-term care, institutionalised with the adoption of Bulgaria's first Strategy for Long-term Care in 2014.

These developments in Bulgaria reflected the growing interest of EU policymakers in long-term care. Long-term care became a key element of EU's economic and social modernisation strategy, launched in Lisbon, due to its perceived contribution to social cohesion/employment (as an active employment policy tool), job creation, and solving the challenges of demographic aging. This led to the establishment of the OMC on health and long-term care in 2004. The Commission strengthened its engagement with long-term care though the adoption of the Social Investment Package[72] which included a separate Commission staff working document on Long-term Care in Aging Societies (European Commission 2013c). Long-term care was also promoted through the European Funds in the 2014-2020 programming period. Thus, the ESIFs Common Provision Regulations (European Parliament 2014:5(3)(d)) urged states to identify measures for 'cost-effective' provision of long-term care services. In addition, the European Social Fund regulations encouraged investments in affordable, sustainable, and high-quality services, including long-term care, to achieve funds' objective related to promoting social inclusion and combating poverty. The EU thus, influenced Bulgaria's emphasis on long-term care in social policy and assistance schemes in the 2014-2020, as demonstrated in the analysis of policy frames earlier in this chapter. The fact that the new to Bulgaria 'long-term care' concept developed recently, following EU promotion, further suggests EU influence.

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[72] The package included two main documents: Towards Social Investment for Growth and Cohesion, which encompassed the implementation of the European Social Fund 2014-2020 and Investing in Children: Breaking the Cycle of Disadvantage, along with a series of Staff Working Documents. The aim of the package was to provide 'guidance to help reach the Europe 2020 targets by establishing a link between social policies, the reforms as recommended in the European semester to reach the Europe 2020 targets and the relevant EU funds' (European Commission 2013b).

The concept of long-term care is closely associated with aging, which can explain the shift towards older people in assistance programmes launched after 2014. Key EU documents, such as the OMC and the Social Investment package, put a strong emphasis on long-term care as a response to demographic problems associated with the aging population. However, EU's perspective on aging, is strongly medicalised, emphasising the need to maximise 'healthy life years' and 'reduce the risk of dependency' through health promotion and health prevention (Council of the European Union 2012). This perspective, when applied to disability policy, risks reinforcing medical model views and negative attitudes toward disabled people. Some scholars have expressed concerns that a 'cure and care' perspective (Schulmann and Leichsenring 2014:5), linked to active and healthy aging, could lead to the devaluation of those who may not fit the conventional definition of active and healthy.

At the same time, the EU's understanding of long-term care is economically productive and labour oriented, linked to EU's dominant focus on economic and market functioning. The adoption of long-term care as a policy issue under the OMC stemmed from concerns about its implication for public finances (Daly 2017). Long-term care is expected, on the one hand, to enable older people to remain active and participate in the labour market longer. On the other hand, it is intended to contribute to employment by allowing relatives, especially women, to reconcile work and caring responsibilities and by creating jobs in the health and long-term care sector. This approach aims to prevent labour shortages, which endanger both the European economic growth and the financial sustainability of member states' social systems.

Choice and control subframe (ESIFs) and human rights (Personal Assistance Act)

Choice and control became an important subframe at the end of the first programming period (2011), primarily influenced by Bulgaria's preparations for ratifying the Convention on the Rights of Persons with Disabilities. The Convention puts strong emphasis on choice, including in its general principles the 'freedom to make own choices' and 'independence of persons' (Article 3(a)).

EU disability policies (European Commission 2005b, 2010b) also reflect the Convention's emphasis on choice and control has also been reflected in however not very consistently. In 2005, the Disability Action Plan 2003-2010, was revised, and choice and control were added as key principles, underpinning the realisation of its measures. Explicit reference was also added to the values of the forthcoming Convention on the Rights of Persons with Disabilities. However, in the 2007 revision, any mention of choice and control disappeared from the Action Plan, and the focus shifted exclusively to accessibility. The European Disability Strategy 2010-2020, while seeking to ensure the effective implementation of the CRPD, also did not stress choice and control. Therefore, the EU's influence on the increased emphasis on choice and control in the framing of assistance services was marginal.

The EU also had limited impact on the framing of assistance as a human rights issue in the Personal Assistance Act. The main influences were the CRPD and the CRPD Committee's interpretation of Article 19. Domestic actors involved in drafting the Act have also emphasised the importance of the CRPD and the limited influence of the European Disability Strategy (Angelova-Mladenova, 2020).

Deinstitutionalisation subframe

Deinstitutionalisation was a new concept for Bulgaria at the beginning of the 2000s. Until the late 1990s, institutions were not seen as a problem, and no efforts were made to reform the extensive system of institutions inherited from the state socialism (see Chapter 3). In the first decade of the 21st century, deinstitutionalisation and development of community-based services became integral to national policies, initially in child protection and later in disability[73]. Thus, assistance services, a became framed in relation to the deinstitutionalisation of adult social care.

Deinstitutionalisation was placed on the government's agenda, largely due to the EC's pressure and financial assistance. From 2001, all EU monitoring reports, criticised the poor conditions and quality of care in institutions and the lack of community-based services, urging Bulgaria to reform its care system. The pressure became even stronger with the 2003 Accession Partnership Agreement where one of the priorities was 'to systematically reduce the number of children in institutional care, in particular through developing alternative social services aimed at children and families' (Council of the European Union 2003:7). At the end of the 2000s, the Commission launched a collaborative exercise with the Bulgarian Government, aimed to support the use of EU funds for the deinstitutionalisation of children (see Chapter 5).

EU deinstitutionalisation policies, which developed in parallel with national policies, had a strong focus on children. A scandal with Romanian orphanages in the late 1990s brought institutionalisation to the EU's attention. It led to imposing childcare accession

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[73] For example, the Strategy for equal opportunities of disabled people (2003), the Plan for reducing the number of children placed in institutional care 2003-2005, the Strategy to combat poverty and social exclusion (2003), and the National report on the strategies for social protection and social inclusion of the Republic of Bulgaria 2006-2008.)

conditionality on Romania in 1999 (Iusmen 2013) and influenced the emphasis on children's deinstitutionalisation in Bulgaria's Accession Partnership Agreement and the subsequent monitoring reports. A similar scandal in Bulgaria in the late 2000sprompted a more direct intervention by the EC (see Chapter 2).

This focus on children in institutions had several important consequences for policy development. Firstly, it resulted in less attention being paid to institutionalised disabled adults. Secondly, the understanding of the problems of institutionalisation and the required responses were strongly influenced by the concept of 'care'. Care is a central idea in children's rights and has a strong presence in the Convention on the Rights of the Child, which the EC used in the early 2000s as a 'borrowed acquis" (Jacoby et al. 2009:114). However, the notion of 'care' is controversial in the disability area because it is associated with the traditional medical approach to disability. As Oliver and Barnes (2012:66) write, 'for many disabled people the concept of 'care' is both patronising and oppressive'. Reflecting this understanding, the Convention on the Rights of Persons with Disabilities only uses 'care' in relation to children, replacing it with 'support' and 'assistance' for adults. Thirdly, the strong focus on children's deinstitutionalisation resulted in community services, including assistance services, being defined in the 2002 revision of the Social Assistance Act as 'services provided in a family environment or an environment similar to a family one' (Additional Provisions, Para. 7). This emphasis on care and the family in the framing of deinstitutionalisation and community services contradicts with the focus on independence, choice, and control promoted by the CRPD and the CRPD Committee's interpretation of personal assistance.

Conclusion

This chapter explored the development of assistance policies in Bulgaria and how domestic policy patterns are connected to existing and developing patterns at EU level. It revealed convergence between assistance-related policy frames and subframes, and the more general EU discourses on activation, inclusion, long-term care, and deinstitutionalisation.

EU's on-going focus on employment as a tool for economic and social development significantly influenced the framing of assistance as primarily an employment issue. The dominance of employment-related considerations led to various restrictions on the eligibility of assistants or the conditions for provision of the service, such as limitations on the age or employment status of assistants. These restrictions constrained disabled people's choice and the flexibility of the service, thereby limiting its ability to support independence and inclusion. However, it was the potential of assistance services to fight unemployment that drove their adoption. Whether this can be seen as a positive development in terms of policy's effectiveness in supporting disabled people's inclusion remains is questionable.

EU's promotion of social inclusion, long-term care, and deinstitutionalisation had a mixed impact on Bulgarian policymaking. On the one hand, the EU's emphasis on social inclusion contributed to a more social understanding of disability, prompting a shift in the focus of assistance schemes from relatives and assistants to disabled people. This shift led to changes in the conditions and organisation of assistance services, making them more flexible and responsive to the individual needs and preferences of disabled people. On the other hand, the emphasis on care and health in the discourse on deinstitutionalisation and long-term care, reinforced the already strong medical perspective towards disability issues and a patronising approach to disabled people as passive recipients, not active participants. Thus, it hindered the development of personal assistance as a service that supports disabled people's independence.

The EU influence on the framing of assistance as choice and control and the adoption of a human rights perspective was relatively weak. I these areas the Convention on the Rights of Persons with Disabilities and the domestic civil society actors played a more important role. Yet, despite the recently strengthened emphasis on choice and rights, the transformation of the assistance service from home care to an empowering form of support for community living was hindered by the prioritisation of employment and a medicalised understanding of disability. Domestic non-state actors also failed to challenge the status quo, despite their success in influencing legislation.

Chapter 5. NGOs' willingness and ability to foster domestic change

This chapter focuses on disability NGOs and explores their ability and willingness to foster domestic change in the context of Bulgaria's EU accession and membership. Building upon the discussion of the EU's influence on NGOs in Chapter 1, it first looks at how NGOs' organisational capacity and goals and their participation in policymaking have been affected by funding and pressures on the state to create an enabling environment for NGO involvement. Then it goes to analyse NGOs' efforts to use the opportunities created by the accession and membership to strengthen their policy influence, including mobilising external pressure, establishing contacts with transnational networks, and linking demands to existing EU priorities and regulations (framing). The analysis is based on a review of documentation and interviews with key actors, including domestic and European NGOs, civil servants, and European Commission officials.

NGO capacity and goals

Access to financial resources is a key factor for the development of NGO capacity to pursue their goals (Carmin and Fagan 2010; Smith et al. 2018). As discussed in previous chapters, the growth and development of the NGO sector in CEE, including Bulgaria, have been strongly influenced by external funding. While not without controversy (Ishkanian 2003, Fagan 2006, Börzel 2010, Salgado 2014), foreign donors' support in the first days of transition allowed NGOs to strengthen their administrative capacity, build expertise in various areas and engage in a wide range of activities, including advocacy and campaigning (see Chapter 3). The EU accession of the country, however, was accompanied by important changes in funding sources and mechanisms, including the availability of external funding and the replacement of EU pre-accession programmes with the European Structural and Investment Funds. This section will explore their impact on disability NGO's willingness and ability to influence policymaking.

Withdrawal of foreign donors

The withdrawal of foreign donors had strong negative impact on human rights NGOs, for whom external funding had often been the only source of support (see Chapter 3). The resource constraints weakened the capacity of some well-established and visible organisations to engage in direct advocacy – for example, to follow policy developments, to publish statements, to meet with policymakers, and to participate in working groups. On the other hand, it hindered their ability to mobilise supporters, considered as crucial for improving the chances for influence of organisations with more radical viewpoints (Mosley 2011), such as those promoting independent living and human rights in a context where social protection policies are largely informed by the medical model of disability. Thus, the Centre for Independent Living – Sofia experienced more than one 'gap' when it had to survive for weeks or even months without funding; its staff went down from approximately 30 people full-time in the period 1998-2004 to an average of 1-3 people part-time afterwards (Interview NGO). At the same time, due to the lack of funding for such activities, the Centre had to limit or completely abandon its work with grassroot organisations and informal groups of disabled people, which sought to strengthen disability rights advocacy at local and national level by building a network of organisations supporting independent living. This indicates that contrary to the widespread view in the literature that external funding detaches NGOs from their base (Hahn-Fuhr and Worschech 2014), funding can also enable NGOs to remain close to their constituency and engage with them.

Another challenge for progressive disability organisations is the fewer opportunities to form advocacy coalitions. This is because many likeminded organisations and potential coalition partners ceased to exist or moved away from advocacy work due to lack of funding for such activities. For example, following the withdrawals of foreign donors, the Centre for Inclusive Education – a successor of Save the Children (Bulgarian programme) a leading advocate for deinstitutionalisation and inclusion of disabled children – was only able to continue its advocacy work by using resources generated from service provision. Eventually, the organisation directed its efforts exclusively towards the provision of paid services and established an Educational Centre as a core activity hoping that it could help ensure financial sustainability. Policy advocacy is not currently among the priorities of the organisation. The Centre for Inclusive Education was a frequent coalition partner of the Centre for Independent Living, and this shift in priorities meant that CIL's ability to compensate for the limited 'participatory activism' with 'transactional activism' (Petrova and Tarrow 2007) suffered.

The NGOs least affected by the withdrawal of foreign donors are the nationally representative organisations of and for disabled people (see Chapter 3). This is because they are among the few organisations receiving annual subsidies from the state[74], which allows them to cover their main costs, ensuring their sustainability (Interview NGO5). At the end of the 2010s, the amount of the subsidy ranged from 45,000 BGN (approximately 22,000 EUR) to 617,000 BGN (approximately 300,000 EUR). This is

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[74] In 2019, the nationally representative organisations of and for disabled people receiving subsidies from the state were 21, out of a total of 31 subsidised organisations. The remaining subsidised organisations included the Bulgarian Red Cross, cultural organisations, and the Bulgarian Institute for Standardisation.

significantly higher than the average budget of most NGOs, which at that time was under 20,000 BGN (approximately 10,000 EUR) (Open Society Institute Sofia 2017). The lack of specific restrictions on how the funds can be used further benefits nationally representative organisations, allowing them to flexibly use the funds in line with their needs and priorities, rather than donor's conditions. Thus, in a context where the sustainability of most NGOs has been threatened by the reduced funding opportunities, nationally representative organisations were able to rely on regular and stable state funding.

Replacement of pre-accession funds with the European Structural and Investment Funds (ESIFs)

When Bulgaria joined the EU, it gained access to the European Structural and Investment Funds[75], which aimed to support the economic and social development of the EU by reducing disparities between the levels of development of the different regions and member states. The ESIFs replaced the pre-accession PHARE programme as the main instrument of EU financial assistance in Bulgaria and other CEE member states.

A crucial difference between ESIFs and pre-accession programmes is the role of the state in the management of the funds. While in pre-accession programmes part of the money was distributed directly to NGOs by the European Commission, ESIFs are managed by the state through different ministries or units within the ministries (Managing Authorities)[76]. The procedure is the following: the EC defines strategic

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[75] ESIFs include five funds: the European Regional Development Fund, European Social Fund (ESF), the Cohesion Fund, the European Agricultural Fund for Rural Development, and the European Maritime and Fisheries Fund.

[76] In Bulgaria, although a regional division was introduced in 2000 and further regulated with the Regional Development Act (2004), the distribution of EU funds remained centralised. In some Member States, including the

priorities for each programming period (usually covering seven years); based on this and taking into account the specific circumstances in the country, the state puts together national plans (Operational Programmes); the plans are reviewed by the EC and revised, and the funds are then disbursed to the state, which issues calls for tenders through the relevant Managing Authorities. The specific focus of the calls, the time frame and the beneficiaries are determined by the state.

The shift from pre-accession funds to ESIFs put national authorities in a position of ‘powerful gatekeepers of EU funding’ (Sudbery 2010:152) when it comes to national priorities, approaches for their achievement and beneficiaries. Together with this, in the context of limited external funding, the concentration of significant financial resources in the hands of the state allowed the government to influence NGOs’ agendas and development by directing funding towards specific areas or activities, such as service provision, leading to financial dependency and ‘goal displacement’ (Crepaz et al. 2021). This section will examine how the priorities and conditions of the ESIF calls have negatively influenced disability NGOs’ potential to challenge the status quo, by exploring their transformation into service providers and subcontractors.

The first step towards increased NGO engagement with service provision was made several years before the start of the Operational Programmes and was associated with EU-influenced amendments in the Social Assistance Act in 2003. During the period of intensive negotiations on Chapter 13 (Employment and Social Policy), the Commission called on the country to strengthen the role of NGOs in the provision of social services

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Czech Republic and Poland, the management of EU funds is decentralised, and regions are involved in the development and management of EU-funded programmes. However, this process has not been without challenges (Dąbrowski 2014).

for socially excluded groups, focusing on disabled people and ethnic minorities (European Commission 2001b:62). While opinions expressed by the EU do not have an obligatory nature, the desire of the candidates for EU membership to show progres makes them keen to react to recommendations (Raik 2006: 323). Thus, shortly after the EC's recommendation, Bulgaria formally confirmed its commitment to make changes in the Social Assistance Act and to open the provision of state-funded services to private organisations (Government of Republic of Bulgaria 2002). In 2003, the changes were already a fact, and in 2004, the first procurements for services were announced.

Within the framework of the ESIFs, disability organisations had an opportunity to submit proposals in two types of calls for tenders – general and disability specific. The general calls were open only for NGOs and sought to develop their capacity to promote partnerships with the administration aiming to improve the transparency and accessibility of the administration. In the 2007-2013 programming period, three such calls were issued within the framework of Administrative Capacity Operational Programme, providing some opportunities for human rights NGOs to apply for funding. However, these calls were open at the very beginning of the programming period, and the money was distributed between 2007 and early 2008). No further calls were opened after this, leaving the impression that they were only a demonstration of support for NGOs rather than a genuine mechanism for support (Interview NGO3).

The main opportunity for disability organisations to secure funding from the ESIFs was through disability-specific calls issued under the Human Resource Development Operational Programme. These calls usually required eligible applicants, both state and non-state actors, to provide social and other services, thus steering them towards service provision. Overall, service provision dominated the ESIF-funded NGO projects, with nearly 75% of the projects in all areas (including administrative capacity, human resource development and environment) focusing on provision of services (Georgiev and Aleksieva 2015:8). One fifth of all projects delivered assistance services to disabled and older people[77].

The orientation of NGOs towards services, reinforced by the prevalence of such calls in the Operational programmes, made organisations more reluctant to challenge state policies and advocate for disabled people's rights. One of the interviewed NGO representatives noted that there are hardly any organisations left willing to engage in advocacy because 'they are all service providers now' (Interview NGO7). The Bulgarian minister of EU Funds during 2010-2013 openly acknowledged that the operational programmes 'determine a different role for civil organisations – that of a service provider' (Donchev 2011). While he admitted that NGOs' 'true nature' is 'to represent citizens' interests', he pointed out that other donors and programmes, such as the Financial Mechanism of the European Economic Area, should be able to support this function. However, their support, although important, was far more modest, compared to the EU's. After Bulgaria's accession, the EU became the main NGO donor, distributing nearly 100 million BGN (approximately 50 million EUR) to Bulgarian NGOs between 2007 and 2013 solely through the ESIFs (Georgiev and Aleksieva 2015).

Such a link between NGOs' focus on service delivery and their reluctance to challenge state policies has been observed by many scholars (Ferge 1997, Mabbett 2005, Holland

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[77] Analysis by the author, based on data from the Information system for management and monitoring http://umispublic.government.bg/.

2008, Bloodgood and Tremblay-Boire 2017, Mladenov 2018). Analysing disability activism in the Visegrád countries, Holland (2008) finds that organisations providing services tend to favour cooperation in their relations with the government. He distinguishes them from those engaged in advocacy and watchdog roles, who are more likely to adopt a confrontation approach. Fröhlich (2012) observes similar patterns in post-socialist Russia, emphasising the close relationships, or ‘entanglement’, of consensus-oriented organisations with the state.

There has been a debate in the disability literature regarding the place and role of these approaches in CEE countries. Holland and Frohlich view the conflict approach as foreign to these countries, arguing that it is ‘derived from the western, liberal-individualistic model of civil society’ (Fröhlich 2012:371) and promoted by Western NGOs and agencies. They favour the consensus approach, linking it to the specific local context and the legacies of the state socialism. Thus, Holland (2008:549, 550) calls on US and EU organisations ‘to recognize the strong historical trend towards consensus rather than conflict models […] for advancement of disability issues’ and ‘to allocate resources in such a way that this historical trend is respected’. Together with this, Fröhlich (2012:385) views the NGO-state cooperation as ‘crucial for the implementation of social inclusion of the disabled and for the representation of their interests’. However, as Mladenov (2018) notes, prioritising consensus and service provision can lead to the depoliticisation of NGOs and can thus maintain the subordinate role of civil society inherited from state socialism. Therefore, he suggests that in the CEE context “the [p]aradigm of consensual public needs to be interrogated instead of promoted’ (2018:87). Furthermore, given the strong medical understanding of disability in Bulgaria and the lack of political will for reforms (see Chapter 3), it is unlikely that a radical transformation can take place without confrontation.

It should also be noted that while state socialism has undoubtedly impacted CEE civil societies, the consensus orientation of NGOs is not unique to these countries. Mabbett (2005), analysing the implementation of EU social policy in EU member states, observes that disability organisations with ‘institutionalised social policy roles and a degree of structural interdependence with government’ (for example, receiving state funding for services) are more cautious about using confrontational strategies, such as litigation, while radical organisations, seeking major policy change are more willing to confront.

Delivering services on behalf of the state has also influenced NGOs’ priorities, directing their advocacy toward preserving the status quo. Mosley (2011:453) suggests that the advocacy of NGOs providing services may be ‘more about organisational maintenance and protecting the status quo than about social change’. For example, at the beginning of the deinstitutionalisation process in Bulgaria, many NGOs emphasised the need to support all children, including those with impairments, to grow up in a family environment through reintegration and development of family-based services[78] (Interview NGO). However, channelling significant ESIFs funds towards group homes – hundreds of which were built during the de-institutionalisation of children services (Strategma-Balkan Institute Consortium 2019) – led to increased NGO involvement in providing these services, thus shifting their focus towards residential care outside the family. Despite the mounting criticism from international and European bodies and organisations, like the Committee on the Rights of Persons with Disabilities (2017), the Council of Europe’s

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[78] Family-based care, as opposed to residential or institutional care, refers to arrangements whereby a child is placed in the domestic environment of a family (EEG 2012)

Commissioner for Human Rights (2102), the European Network on Independent Living (Parker et al. 2016), and UNICEF (2020), many NGOs actively support and advocate for groups homes. At the beginning of 2019, concerned about potential cuts in EU funding for group homes, six NGOs sent a letter to the Commission supporting future ESIFs investments in group homes and highlighting Bulgaria's 'serious progress in the planning and construction of new residential services' (The Cedar Foundation et al. 2019). Later that year, another statement called for increased state funding for the service (Childhood 2025 Coalition 2019). NGO support for group homes has cemented the status quo, allowing the over-reliance on group homes in the de-institutionalisation process to continue and expand from children to adult services, contributing to a 'façade' inclusion.

Not only were NGOs pushed towards service provision by the state managed ESIFs, but they were also positioned as subcontractors, delivering services according to specific requirements. During the pre-accession period, external donor grants, allowed NGOs flexibility in deciding activities and approaches within the donor's general priorities. In contrast, many ESIFs calls resemble tenders for services more than grants for NGOs. For example, the calls concerning assistance services have very specific requirements, determining the type of services to be provided, the methodology, the hourly rate, thus limiting NGOs' choices to their projects' geographical coverage and the number of participants. These detailed specifications meant that NGOs were unable to 'game' the system by using resources received for service provision to support their advocacy work. In addition, it prevented organisations from developing new support options, that could empower disabled people to live independently and potentially strengthen the independent living movement in the country and its ability to challenge the status quo. Some have suggested (interview NGO3) that restricting NGO innovations had been, a government policy[79] from the very beginning of the ESIF funding.

Organisations receiving funding from the state to provide services are also less willing and able to criticise government policies due to their financial dependence. An interviewed service providers noted that ‘NGOs receiving funding from the state prefer to be milder with their criticism, so they do not have their funding stopped…You can’t criticise the one who gives you the money’ (Interview NGO2). Some children’s organisations, including those working with disabled children attempted to overcome this limitation: ‘That is why we set up an independent network – to say things the rest of us can’t, due to our dependency on state funding. However, this approach did not work as expected (Interview NGO2). Having to balance the interests of its members, many of whom provide state-funded services, the network has not been able to challenge state policies as strongly as some members had hoped. It is even seen by some NGOs as being ‘on the edge of being pro-government’ (Interview NGO7). Thus, the funding dependency of the members of the network limited their potential to use transactional activism to challenge the status quo.

The short-term nature of funding further increases NGOs’ insecurity and conformism. Although ESIFs allow for the implementation of long-term programmes (Interview EC2), the duration of projects supported through Operational Programmes was usually limited to 12-18 months. Even when similar services were provided over a few years, such as

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[79] In the period between 2007 and 2020, Bulgaria was ruled by both centre-left government (2007-009 and 2013-2014) and centre-right government for the reminder of the period, except for a few months when caretaker governments were in charge.

personal and social assistant, they were funded through a series of short-term projects (see Chapter 4). This negatively affected NGOs' capacity for advocacy as they were forced to divert a significant part of their resources to fundraising and administrative work – following calls for proposals, writing project applications, and reporting, which was seen as 'very bureaucratic and challenging' (Interview NGO 6) even by experienced organisations. Many of these challenges were also common during the accession process.

In the second programming period (2014 – 2020), opportunities for ESIFs funding for NGOs were further reduced, as the funding for service provision was channelled to municipalities. Assistance services illustrate this point well. The first scheme, which started in 2007, was open to both municipalities and private providers. The last scheme, however, was only open to municipalities through a direct provision process. NGOs and private service providers could participate as partners of municipalities; however their involvement was constrained by requirements for the municipalities to provide the service directly[80], as well as conditions related to the financial capacity of these partners[81].

The 'devastating impact' (Interview NGO1) of the collapse of external funding on NGOs, coupled with the challenges in accessing ESIFs made NGOs sceptical about the development of the sector and its potential to influence policies. As one of the interviewees summarised the situation: 'The EU membership brought more challenges than opportunities to NGOs. The expectations were that the EU funds would open new

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[80] According to the Guidelines for applicants, the applicants (i.e. municipalities) are directly responsible for the preparation, management, and implementation of the project.

[81] To be able to apply as partners, organisations' financial resources had to be at least 20% of the amount they were expected to spend on the project.

opportunities for NGOs, but this did not happen. They merely fill in the state budget. […] As a whole, the [NGO] sector is headed towards closure' (Interview NGO3).

Involvement of NGOs in policymaking

Throughout the accession process and after that, the EU has promoted greater inclusiveness in the policymaking process. This section explores the institutionalisation of disability NGOs' involvement in policymaking and its impact on their ability to influence disability policies. It focuses on the National Council for Integration of People with Disabilities – the primary consultative body for disability policies and legislation – and the consultative bodies created within the framework of the European Structural and Investment Funds. In line with the many critical accounts of the EU's influence on NGO-state relationships (Fagan and Wunsch 2018, Kutter and Trappmann 2010, Noutcheva 2009, Börzel and Buzogany 2008, Gąsior-Niemiec 2007, Börzel and Pamuk 2012) it demonstrates that disability NGOs' involvement in policymaking has often been formal and provided very limited opportunities for influence. Moreover, as the next section will show, the 'creation' of nationally representative disability organisations and their selective involvement in the policy process has enabled state actors, reluctant to engage with NGOs, to neutralise critiques and maintain the status quo.

National Council for Integration of People with Disabilities (NCIPD)

NCIPD was established in 1995, during the early stages of Bulgaria's EU accession period, even before the start of official EU membership negotiations. However, the EU did have an important influence on the formation of the NCIPD, its structure, positioning, and legitimacy, initially through diffusion, the transfer of ideas and models, and later, through political influence.

The Council was established by the Protection, Rehabilitation and Social Integration of Invalids Act (1995). The Act and its provisions related to the structure and functioning of the NCIPD were significantly influenced by the experience of Belgium[82]. The creation of the NCIPD was also informed by European ideas and models, through the National Tripartite Council. The Tripartite was set up two years prior to the NCIPD, drawing inspiration from best practices in continental Europe (Spasova and Tomini 2013; Iankova 2000), including the approach to determining the legitimacy of social partners to participate in the consultations[83], a highly controversial issue in the NCIPD's operation. At the time NCIPD was established, Bulgaria's experience with participatory policymaking was limited to the area of social dialogue, the importance of which was growing.

NCIPD adopted a quasi-tripartite structure, involving state representatives, employers of people with disabilities and organisations of and for people with disabilities[84]. Like the Tripartite, only organisations recognised as representative, i.e., that met the state-defined criteria for representativeness, could become members. These criteria were exclusively based on numbers and including geographical coverage and membership for disability organisations and number of clients and specialised staff for service providers (Council of Ministers 1996).

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[82] During that period, strong partnership relations existed between a domestic service provider, the National Centre for Social Integration, and the Belgian Disability Forum (Koeva 2014). Policymaking in Belgium is characterised by a dense advisory system incorporating a number of advisory councils into the policy-making process, including in the area of disabilities (Fobé et al. 2013).

[83] The criteria for representativeness of social partners in the National Tripartite Council are similar to those used by many EU Member States, such as Austria, Belgium, France, Germany, Ireland, Italy, Portugal and Spain. These criteria typically focus on membership and territorial coverage (Eurofound 2016:21).

[84] In 2004, following the amendments in the Law for Integration of People with Disabilities, trade unions were also included.

The EU, with its political support for NGO-state cooperation (see Chapter 2) helped legitimise the existence of the NCIPD. During the pre-accession period, the EU put ‘soft’ pressure on Bulgaria through explicitly expressed opinions, critiques, and recommendations to include NGOs and other key actors in the policymaking process (European Commission 2000d, 2003c). NCIPD was cited as a good example of NGO-state partnership in the social area In one of the EC’s regular monitoring reports, alongside the Council for Child protection and the Council for Social Assistance (European Commission 2003c). This positive assessment reinforced the formal legitimacy of the Council as a consultative body.

The EU’s pressure also contributed to strengthening NCIPD’s legal framework. In 2001, an amendment in the Protection, Rehabilitation and Social Integration of Invalids Act, introduced a mandatory requirement for all legal acts concerning the rights of disabled people to be adopted only after consultations with the NCIPD. A similar amendment was made in the area of social dialogue a year earlier, strongly influenced by the EU (Spasova and Tomini 2013:16).

The creation of NCIPD established a dedicated channel for the participation of disability NGOs in policymaking. While this improved NGOs access to policymaking, it also allowed the state to gain legitimacy for its policies from a traditionally oriented and depoliticised Council, simultaneously weakening the critiques of disability organisations not represented in the Council. As a result, the existing medical model policies remained unchallenged. This section examines how the composition of the Council, the funding dependency of its members on the state, and its formal involvement in policymaking have contributed to this situation.

Formal involvement

Façade involvement in consultations is a common barrier to NGOs' ability to influence policies in CEE countries (Börzel and Buzogany 2008, Kutter and Tappmann 2010) and elsewhere (Arnstein 1969). Despite being established as a consultative body, the government did not seek advice from it, but rather its endorsement of policies. An NGO representative on the NCIPD shared that initially, state institutions did not acknowledge the consultative role of the Council: 'I assume that since they were giving money to the nationally representative organisations, the [state] institutions thought that somehow, we were one of their structures. It was very difficult to convince them that we are not' (Interview NGO5).

As a result, the approach to consultations, especially in the first years, was quite formal. Important Bills and policies were often not presented to the Council for discussion, amendments were made without consultation, and the Council was merely informed, rather than involved in the development of policies. Event when the government's proposals were discussed in the Council, the recommendations of the Council were generally not taken into account (Nationally Representative Organisations of People with Disabilities and for People with Disabilities 2008). Furthermore, with the increase in the number of disability organisations in the Council (21 in 2019), the number of representatives from state institutions also increased (from 8 until 2004 – to 20), allowing the government, with the support of a couple of the other Council members[85], to

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[85] Including 5 organisations representing employers, 2 trade unions, and the Association of municipalities in the Republic of Bulgaria.

maintain a majority when voting.

Access to NCIPD

Access to policymaking is crucial for NGOs' ability to influence policies. In the CEE literature, access to policymaking is usually linked to professionalisation of NGOs – the more professionalised and prominent organisations are often invited and find it easier to engage in policy consultations, while smaller organisations are marginalised (Ishkanian 2003, Gąsior-Niemiec and Gliński 2007, Ivancheva 2015, Fagan and Wunsch 2019). The NCIPD case, however, offers a somehow different perspective: here an NGO's eligibility to participate is determined by the size of its membership base, which is considered a measure of its representativeness. Before going on to discuss the implications of this for NGOs ability to access and influence policymaking, I will briefly explore various perspectives on the concept of representation.

The traditional view holds that representativeness is determined by numbers and requires 'counting heads' (Dryzek 2000:84) or votes. The implicit assumption is that a given group has a stable set of interests that can be represented by someone authorised (Guasti and Geissel 2019). This understanding has been challenged by scholars like Michael Saward (2006, 2009), who argues that there is a variety of 'representative claims', some highlighted and others crowded out by those making them. He points out that the traditional representation will always involve a certain degree of 'misrepresentation' (Saward 2009: 5). From a disability perspective, Mladenov (2009) problematises the traditional understanding of representation using the concept of 'needs, a key concept in the social policy, arguing that needs and interests are constructed in the process of their identification. '[T]he understanding of 'what people need' depends on who asks the question and what the respondents expect to gain from the inquirer(s)' (Mladenov 2009:41).

There is an alternative perspective on representation, which includes other factors like tradition, expertise and special credentials, or stakeholding (Saward 2009). Scholars studying NGOs' political activities in the CEE suggest that an organisation's legitimacy can come not only from its membership size but also from its expertise and capacity to provide substantive input into the policymaking process, a 'think-thank' type of legitimacy (Wunsch 2018: 126), or from its 'value commitments' and 'track record in fighting for equal opportunities of disabled people' (Mladenov 2009:43).

In Bulgaria, most consultative bodies involving NGOs adopt eligibility criteria different from those of NCIPD, usually based on experience or expertise. For example, the Council for Child Protection, established in 2001, requires NGOs to work in child protection to be eligible to become members. Similarly, the Council for Cooperation on Ethnic and Integration Issues, formed in 2006, demands 3 years of activity in line with the Council's objectives. Some NCIPD participation criteria also refer to experience but only recognise that gained through provision of services.

The NCIPD criteria for representativeness, focusing on membership/client numbers and geographical coverage, favours organisations providing services, including parents' organisations, and traditional disability organisations. Most NCIDP members since its inception belong to these categories. However, this approach excludes grassroots and major human rights organisations, such as the Centre for Independent Living and the Bulgarian Helsinki Committee, which focus on broader issues or specifically on disabilities. These membership criteria serve as a barrier for critical human rights organisations, a common strategy in corporatist systems (Bloodgood et al, 2014:717), resulting in Council dominated by organisations with traditional medical views.

In addition, the composition of the NCIPD discouraged critical organisations, capable of meeting representativeness criteria from seeking membership. Their reluctance stems not only from concerns about the state's formal stance towards consultations or losing independence as state partners (Börzel 2010, Gąsior-Niemiec and Gliński 2007), but also from the realisation that challenging the strong medical consensus in the Council would be impossible (interview NGO1 and NGO7).

Representativeness and funding

In addition to providing access to the NCIPD, an organisation's representative status enables it to receive annual state subsidies. This reliance on state funding, as previously discussed, can erode organisation's autonomy, leading to a reluctance to challenge state policies due to concerns over the potential cessation of funding can be stopped. Moreover, the link between representativeness and funding has been a stimulus for NGOs, not necessarily interested in policymaking, to join the Council. These organisations use the state funding for their core activities, usually service provision, while their capacity to influence policies remains limited. For example, one interviewed NCIPD member noted that despite needing to provide comments on draft policies and regulations on a regular basis[86], their organisation lacks in-house legal expertise or consultancy support. Relying on external experts leaves insufficient time for comments

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[86] With the amendments to the Disability Act, the government was required to consult the NCIPD on all draft policies, before adopting or submitting them for discussion in Parliament.

and negatively affects submission quality – 'It is difficult for us to manage to do it within 5 days as we have other day-to-day work. […] Lately, it often happens that our comments are amateur because we have not found the time or the expert' (Interview NGO5). Furthermore, the interviewee argued that despite the organisation's membership in NCIPD and the expectation to comment on policies, the state funding is not intended to support their policy work.

Impact on NGOs' political activities

The institutionalisation of the NCIPD did not significantly enhance disability NGOs' ability to influence policymaking. The formal approach to consultations, especially in its early years, limited NCIPD members' opportunities to express their opinions on key policies or resulted in their recommendations not being considered. Over time, while meetings of the Council became more regular, their formal character remained (Interview NGO1).

Together with this, the legally prescribed role of the Council as a state partner favoured consensus over criticism and conflict. This approach did not encourage challenging the foundations of the country's disability policy – 'They prefer discussing technical and financial details within the framework of the new law, which in philosophy and in essence differs little from its predecessor' (Interview NGO1).

In addition, the traditional views of nationally representative organisations ensured their support for the status quo, even in the face of problematic policies and practices, such as institutionalisation. For example, in 2002, on the initiative of the nationally representative organisations of/for disabled people, the NCIPD officially condemned an

Amnesty International report critical of the situation in residential institutions (NCRSI 2002). More recently, these organisations opposed demands by mothers of disabled children for adoption of personal assistance legislation (NCIPD 2018). While there have been disagreements between disability organisations in the Council and the government, leading to critical public statements and even protests (in 2007-2008 and 2018), the demands raised – for increase of disability benefits or against disability assessment reform – did not radically challenge the status quo. Overall, the state and the nationally representative organisations have consistently emphasised their partnership (Hristova 2002:5, Georgiev 2005:4, Indjova 2005:6).

At the same time, NCIPD has impeded the ability of non-represented organisations to foster policy change. For example, the state has used NCIPD's legitimacy to justify policies and dismiss inconvenient NGO demands, claiming regulations are 'enforced with the consent of the National Council' (National Administrative Court 2006). The European Commission has also used the legitimacy of consultations with representative disability organisations to disqualify critiques from domestic and international organisations regarding the use of EU funds for institutionalising disabled people (see Chapter 4), thereby reinforcing the National Council's legitimacy, and empowering the state while silencing critical voices.

The legitimacy of critical human rights NGOs was also undermined by the quantitative definition of representativeness adopted by the state. During accession, generous foreign donor funding allowed these organisations to establish alternative legitimacy through visibility (e.g., organising public events and campaigns), international recognition (e.g., by inviting foreign experts), producing know-how (e.g., conducting research, organising study visits), and mobilising support from politicians, public figures, and disabled people. However, with the decreased access to funding post-accession, this legitimacy gradually faded away, making policy influence more difficult.

Organisations in the Council actively sought to exclude other NGOs from policymaking to protect their privileged access to policymaking and funding. In 2002, nationally representative organisations successfully proposed changed to the criteria for representativeness[87] which allowed the Association of Deaf-Blind People to remain in the NCIPD, because ‘we cannot attack organisations that have already been members of the Council’ (Velchev 2002). More recently, they criticised the government’s Project for a Strategy for Civil Society Development (2012-2015) for its focus on supporting citizens’ participation in decision-making and NGO involvement in the management of state funding. They disqualified these proposals by labelling them as initiatives of ‘interest groups, seeking to protect political and financial interests’ (Nationally representative organisations of and for disabled people, n.d.:3-4) and ‘unwilling to establish and follow clear administrative and financial reporting mechanism’ (ibid: 6).

Many of the issues outlined above are linked to the limitations inherent in the corporatist model of policymaking, which underpin the establishment of the NCIPD. In corporatism, policies are developed in consultation with peak associations, representing the main interest groups. Bloodgood et al. (2014) note that this arrangement can create incentives for governments to maintain the political status quo and restrict access of “unwelcome organisations”. The NCIPD case shows that members of such structures,

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[87] The criteria for organisations of disabled people required at least 1600 members, while for the organisations of deaf-blind people, this requirement was revised to 400. A concession was also made for organisations of little people, which need to have at least 150 members.

including NGOs, can also seek to block the entry of new organisations that could disrupt the consensus or challenge their favourable position. Similarly, in France, organisations entrenched in neo-corporatist structures have strongly opposed proposals for legislative changes that might diversify representation and limit their involvement and influence (Baudot, 2018). In both France and Bulgaria, the push for inclusive policymaking, driven by EU policies and human rights discourses, has ironically resulted in strengthening the positions of the oldest stakeholders in the sector.

The emphasis on consensus in corporatist systems also makes it challenging to implement policy change, especially radical change. Thus, Vanhala (2015) associates the paradoxically late and minimal introduction of disability rights legislation in Denmark with the country's traditional, collective, consensus-based approach to social policymaking. She argues that the main barrier to adopting a Danish anti-discrimination law in the 1990s and early 2000s, was strong opposition from the Danish Disability Council – a neo-corporatist body similar to the NCIPD – which saw the rights-based model as incompatible with Denmark's traditional cooperative approach.

Yet, corporatist structures do hold a potential for internal change, which in turn could affect shifts in policy. In Denmark's case, some members of the Danish Disability Council became more supportive of the rights-based approach following their participation in the CRPD negotiations, leading to the adoption of a Danish anti-discrimination law in 2004 (Vanhala 2015). However, this occurred later than in other North European countries[88], and the law's scope was limited to employment.

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[88] For example, Sweden and the UK adopted such laws in the second half of the 1990s.

In CEE countries, including Bulgaria, the potential for change within corporatist structures has been constrained by their original purpose. According to Ost (2000, 2011) tripartite structures were introduced in CEE to secure complicity with externally imposed neoliberal policies, rather than as a genuine means for compromise or stakeholder involvement in policymaking, as seen in Denmark. The NCIPD, viewed by the government as a tool for policy legitimation rather than genuine consultation, exemplifies what Ost describes as ‘illusory’ rather than ‘transformative’ corporatism.

European Structural and Investment Funds – the partnership principle

As discussed in Chapter 2, The EU partnership principle, which requires the states to interact with non-state actors in the development, implementation, and evaluation of programmes, has been a key element of the EU funding in recent decades. The EC’s desire to ‘deepen’ the scope of partnership – ensuring that partners are adequately involved at various stages of the process – even led to the adoption of a legally binding Code of Conduct on Partnership in 2014. The Code formulates common principles and provides guidance to member states on key aspects of partner involvement.

In terms of the institutional framework, the main ESIFs partnership structures are the Monitoring Committees. member states are required to establish such committees to review programme implementation and progress towards achieving their objectives. States are also encouraged to involve partners in preparing partnership agreements and operational programmes. This includes participation in identifying and analysing needs, defining or selecting priorities, and allocating funding (European Commission 2013c: Art.8). However, there are no specific requirements about the format of these consultations. Countries are called upon to select ‘the most representative relevant partners, in accordance with their institutional and legal framework' (European Parliament and the Council of the EU 2013: Art5).

ESIFs consultative bodies in Bulgaria

In response to the EC's requirements for partnership, the Bulgarian government set up working groups to draft the country's operational programmes and monitoring committees to oversee the implementation of the ESIFs programmes. However, the governments' reluctance to engage with NGOs beyond the minimum compliance with the partnership principle led to a consultative process characterised by late and formal NGO involvement, a lack of transparency, and restricted access. This limited the ability of NGOs to influence ESIF-funded programmes and projects. These issues have also been characteristic of NGO-state relations in other countries in the region, both within and beyond the ESIFs framework (Gąsior-Niemiec 2010, Potluka et al. 2017, Demidov 2017).

During the 2007-2014 programming period, the working group for drafting 'Human Resource Development' Operational Programme, particularly relevant for the disability sector, was selectively appointed by the Ministry of Labour and Social Policy, without clear and transparent criteria. The group did not include NGOs, except for the association of municipalities and the association of provosts of higher educational institutions. Nationally representative disability organisation, however, were involved as members of the NCIPD, which was one of the two consultative bodies in the group, alongside the Council for Cooperation on Ethnic and Demographic Issues). The selective involvement of traditional organisations ensured consensus on the main principles for using ESIFs to address issues faced by disabled people. The group's work was marked by a lack of transparency. Not only there was no publicly available information while the group functioned, but even today, the government is reluctant to disclose details about its composition or work[89]. The lack of transparency limited NGO's ability to monitor the consultative process and influence it from the outside.

In addition, the Monitoring Committee, established in 2006, did not include any NGO members for its first two years. It was only in March 2008, through a Council of Ministers Ordinance, that the NCIPD (with 1 representative) was included in the Committee, although it did not obtain full voting rights until later the same year (Council of Ministers 2008a and 2008b). At the end of the year, following the belated adoption of the Procedural Rules for NGO participation, six other NGOs – specialising in human rights, education, Roma integration, public health, science and social services – were included in the Monitoring Committee's meetings. They were selected through a public call for expression of interest, based on criteria related to legal status and experience. The qualifying organisations were then required to decide among themselves who would represent them in the Monitoring Committee. The reluctance of the state to involve NGOs was further confirmed by the interviewed former civil servant (ICS1), who revealed that the staff of their institution had been instructed by a Deputy Social Minister about the distinction between state institutions and NGOs and the need to ensure NGOs 'know their place'.

While the open call and the broader selection criteria allowed human rights

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[89] The existence of the group is only mentioned in the Programming Document for the Human Resource Development Operational Programme, where it is listed as one of the bodies involved in the preparation of the programme My request for information, submitted in 2018 under the Law for access to public information, was rejected by the Ministry of Labour and Social Policy on the grounds that the information about the 2007-2013 operational programme is not of public interest, since the programme is already completed.

organisations, including those focus on disability, to participate in the main ESIFs consultative bodies at domestic level[90], their ability to influence policies remained hindered at three levels. First, the selection mechanism did not allow direct representation of all issues by the organisations, as the group included NGOs working in various areas, such as disability, Roma, democratisation, and NGOs[91]. Second, the NGOs' status as observers with advisory vote meant that while they could express their views, their votes were not counted in decision-making. This formal approach to consultations has been problematic in many countries (Interview EC1), leading the EC to propose a specific provision for equal voting rights of partners in the ESIFs regulations for the 2021-2028 period. Third, NGO were involved only after the programmes or calls had been drafted, allowing them to comment only within the already established framework by the relevant institutions, rather than to influence policy priorities. As one interviewed NGO representative noted, 'The involvement occurs after the foundation is already laid. If you do not approve, a new programme would need to be developed, which of course, they [the Ministry] will not accept.' (Interview NGO1). Thus, while it was possible to discuss the number of people placed in small group homes (albeit with limited chances for success), the fundamental decision to invest in group homes instead of exploring other support options, was not open for discussion.

In the second programming period (2014-2020), due to the EC's increased emphasis on partnership, two important changes were made in the relevant domestic regulations, theoretically creating better opportunities for NGOs to influence policymaking. First, a mechanism for selecting NGOs in the working group for drafting the Operational

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[90] However, informal groups and less experienced organisations continued to be at a disadvantage.

[91] The Centre for Independent Living was chosen to represent the group of human rights organisations.

Programmes was developed (based on the previously above mechanism for participation in the Monitoring Committee). Second, NGOs became full members of the Monitoring Committee with full voting rights. In addition, the transparency of both structures significantly improved, with more detailed information being made available online[92]. The participation of NGOs in the Monitoring committee was further transformed by the creation of sub-committees, which some NGOs saw as allowing for more thorough examination and discussion of calls (Interviews NGOs 3 and NGO5).

Despite these changes, NGOs' capacity for influence remained limited by their late involvement in the policy process and by the formal nature of the consultations, which was 'steered' in a specific direction by state actors seeking 'to get approval for some documents' rather than a 'debate' (Interview NGO4). The practice of selective involvement also continued, but in less visible structures to the EU, such as working groups coordinating the implementation of ESIF-funded projects.

Nationally representative disability organisations have been more successful in influencing the allocation of ESIFs funds. However, as discussed earlier, this did not involve challenging the underpinning values and principles. Their assessment of their impact is much more positive regarding the operational programmes – 'We can propose operations. […] They hear us. We are satisfied' (Interview NGO5) – than regarding the work of the National Council for Integration of People with Disabilities – 'Sometimes they [the government] agree, sometimes they don't' (Interview NGO5). Three factors contributed to their success: First, access to the NCIPD allowed nationally

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[92] However, the start of preparations for the 2021-2027 programming period raises serios concerns about the sustainability of these positive developments, as the quality of information regresses to the levels observed during the 2007-2013 period.

representative organisations to propose initiatives, not just comment on existing ones, and to mobilise support from other NCIPD members. Second, their proposals were in line with existing government policies – for example, funding for new workplaces in special enterprises and cooperatives for disabled people (NCIPD 2014) –thus posing no threat to the status quo. Third, the state used the EU funds to safely reward these organisations, securing their future support. ‘Safely’ because ESIFs projects are typically short-term and do not require changes in policies, legislation, or long-term financial commitment from the state. For example, in both the 2007-2013 and 2014-2020 programming periods, there were calls where only nationally representative organisations of and for disabled people were eligible to apply[93]. Their combined budget was 13 million BGN (approximately 6.5 million EUR). Restricting applicants to nationally representative organisations allowed the government to bypass the ESIFs principle of non-discriminatory and open selection, which requires all potential candidates able to perform a job, to have access to the procedure (de Buggenoms 2017).

Interestingly, NGOs varied experience in influencing the consultative process resulted in different perspectives on the nature and extent of EU involvement. The most satisfied organisations, representative organisations of/for disabled people, emphasise the close EC monitoring and control, which legitimises restricted calls for proposals from which they benefited – ‘[e]verything is consulted with the EC. The Monitoring committees are limited by the EC rules. Everything is limited by the EC rules.’ (Interview NGO5). On the other hand, organisations critical of government policies question the EU’s genuine engagement, especially in areas with weak acquis, such as disabilities – ‘They [the European Commission] are not interested in the process. They are mostly interested in

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[93] For example, BG051PO001-5.1.05 ‘Compassion’ in 2012 and BG05M9OP001-2.011 “Equal chances” in 2017

the paper reports. […]' (Interview NGO1). Despite their opposing views, both types of organisations recognise the importance of EU's actions or inactions on the consultative process.

The inability to influence the use of ESIFs in Bulgaria led to a growing dissatisfaction among NGOs with EU funds, which came to be seen more as a hindrance than an opportunity. As one interviewee put it, 'The bad situation was cemented, but with lots of money. We are waiting for the EU money to stop, so that we can start fixing things' (Interview NGO6). The EU's strong focus on absorption, especially in the early years of the ESIFs, also instrumentalised the process by emphasising spending over outcomes.

At the same time, the formal character of consultations led to disillusionment and even withdrawal of many NGOs from participation in consultations:

> At first, I believed it would be possible to influence the decisions related to the programming of the funds, but I sobered up quickly. […] We did not apply [for participation in the 2014-2020 Monitoring Committee] because I find it demagoguery in which I don't think we should participate. […] NGO involvement, especially of human rights organisations, is demagoguery. Inclusion is reported, but participation is not guaranteed.' (Interview NGO1)

> 'We had ideas for reforms in the social sector. After our experience in the working group, we stopped being active [politically]. We haven't followed the developments; we haven't even had a desire to participate.' (Interview NGO4)

> ‘We stopped attending such formations [ESIFs consultative bodies] because we don’t have any influence on the decisions.’ (Interview NGO7)

> ‘I don’t think we participated; we were only present at the meetings.’ (Interview NGO2)

Similar processes have been occurring in other CEE countries. For example, analysing the development of ESIFs partnership in Hungary, Poland, Slovakia, and Slovenia, Demidov (2017: 247) notes that the first wave of NGOs, mostly human rights organisations, withdrew from participation in consultations after the end of the first programming period and were replaced by professional service providers. He attributes this to the government’s shift from partnership as deliberation over priorities in the early post accession years towards a more technical focus on collecting expert input and expertise-based policymaking. In Bulgaria, there has never been a process of genuine discussion of priorities, although NGOs did expect this to happen (Interview NGO 1,2,3).

For some Bulgarian NGO activists, the disillusionment went even further, affecting their confidence in the ability of NGOs to affect change: ‘I used to defend the idea of civic participation fiercely and devotedly. After many years of personal experience, I have found that civic participation can be harmful, especially when it comes to radical action.’ (Interview NGO1).

Mobilising external pressure

This section turns the attention from EU pressure and financial assistance towards the opportunities provided by the accession process and context, and how NGOs used these to influence policy. Using the case of deinstitutionalisation, it examines the attempts of NGOs to mobilise EU pressure. This involved utilising EU policies and priorities as a point of reference (framing) and maintaining contacts with transnational networks for knowledge, experience, and political support. The analysis shows that contrary to the expectations of less effective use of EU pressure after accession and in areas where EU has limited competence (Sudbery 2010), NGOs successfully utilised membership opportunities to influence a shift in domestic policies towards deinstitutionalisation. This shift, however, turned out to be more of the same rather than a radical transformation of disability policies (Mladenov and Petri 2020a).

Deinstitutionalisation refers to reforms aimed at replacing the existing system of large-scale institutions with community-based services, enabling disabled children and adults to be included and participate in the public life. Despite Bulgaria's commitment to social inclusion, as expressed in the Social Assistance Law (Chapter 3), little progress was made in reforming social care system. At the time Bulgaria joined the EU, institutions remained the only option for those unable to rely on significant informal care and support.

Attempts for influence during pre-accession

At the beginning of 2000s, realising the lack of domestic political will for reforms in deinstitutionalisation (Iusmen 2016:174) and seeing the opportunities presented by the opening of membership negotiations, Bulgarian NGOs increasingly sought to bring the issue of institutionalisation to Brussel's attention. They participated in meetings organised by the EC, sent information and signals to the Commission, and prepared Alternative reports on Bulgaria's progress towards accession (Coalition of NGOs 2004).

The EC welcomed NGOs' contributions – 'In the pre-accession period, the European Commission had less information about what was happening in the country and had to rely on what the country reported…. To complement the information, I was reading reports from NGOs and the Delegation' (Interview EC2).

NGOs successfully mobilised external pressure for deinstitutionalisation measures. The revised 2003 Accession Partnership Agreement (Council of the European Union 2003:6) included a requirement for Bulgaria to reform its childcare system to reduce the number of institutionalised children by developing alternative support. This led to the government's swift adoption of a Plan to reduce the number of children in institutions 2003 – 2005. A New Social Policy Strategy was also adopted around the same time, which *inter alia,* envisaged a decrease in the number of institutionalised adults. In subsequent years, the Commission continued to call for effective implementation of the adopted policies in its monitoring reports (European Commission 2004 and 2005c).

NGOs' success was largely enabled by the framing of institutionalisation as a human rights issue. Aware of the acquis; limitations in the social area, NGOs linked their demands to the country's human rights obligations[94] – 'All our attempts to influence the EC have been through human rights, not disabilities, because disabilities are not under the EU's competence…' (interview NGO1). The EC's pressure on Bulgaria was framed within the context of the Copenhagen criteria rather than the Social Policy and Employment acquis (European Commission 2004 and 2005c). At the same time, the Commission's pro-active attitude and country missions made it easier for domestic

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[94] One of the Copenhagen criteria that Bulgaria had to satisfy to become an EU member was respect for human rights.

organisations to address the EC, even without extensive knowledge of how the EU works or contacts in Brussels. The expertise and experience of staff from foreign organisations operating in Bulgaria proved helpful for NGOs in their interactions with the EC (Interviews NGO2, NGO3).

However, the EC's soft pressure failed to trigger a process of comprehensive reforms leading only to 'piecemeal initiatives' (Iusmen 2016: 174). Although the 'powers of leverage and coercion' (Sudbery 2010:145) in the pre-accession period allowed the EC to put strong pressure in areas with weak acquis (Jacoby et al. 2009), Bulgaria's reluctance led to fake or partial compliance. A specific challenge in the disability area, was the EC's lack of expertise in deinstitutionalisation, resulting in mixed messages – calls for improving living conditions in institutions while at the same time advocating for their closure (European Commission 2006b, Ivanova and Bogdanov 2013).

EU membership and NGOs successful mobilisation

The accession of Bulgaria changed the dynamic of the relationships between the EU and the country, as the national administration became a 'powerful constituent part' (Sudbery 2010: 145) rather than outsider, and the EU lost its leverage. The new situation was expected to have a negative impact on NGOs' ability to mobilise external pressure, as the EU institutions became increasingly unwilling to intervene (Sudbery 2010; Wunsch 2018). Bulgarian NGOs were aware of the unfavourable post-accession situation – 'After the accession we lost interest [in working with the European Commission] as it was clear that the Commission would try to be more balanced in its relations with the government' (Interview NGO 3).

However, the European Funds opened new opportunities for NGOs dissatisfied with the status quo to mobilise external pressure in areas with weak acquis. As one of the interviewed EC representatives commented, ‘The EU can’t intervene [in areas where it does not have competence], but the EU funds can help’. The numerous obligations on the state – to develop programmes, submit reports, involve the Commission in the Monitoring Committees – serve as indirect control mechanisms, providing ‘many opportunities for the Commission to express its policy preferences and pressure national and regional authorities to comply with them’ (Piattoni and Polverari 2016:116).

Bulgarian NGOs used the opportunities provided by the European Structural and Investment Funds to pressure the government to start comprehensive process of deinstitutionalisation. Several organisations formed an informal alliance advocating for the closure of all institutions for children, including disabled children, and the development of alternative community services. At the same time, there was increasing mobilisation among European NGOs, lobbying the Commission to stop ESIF investments in institutions and redirect the money towards alternative community support.

NGOs’ efforts were successful – the EC intervened and launched a collaborative exercise with the Bulgarian government, which sought to ensure that EU funding would be used to address the situation of institutionalised children (ECCL 2010). As a result, over 30 million EUR from EU funds were ring-fenced for deinstitutionalisation, escribed as ‘a little bit exceptional’ by the EC (Rasmussen 2010) since it happened after programmes had been finalised. The Bulgarian government adopted a strategy and action plan for deinstitutionalisation, financially supported by the EU, leading to the closure of 130 institutions for children with disabilities and children deprived of parental care. The initiation of these reforms was praised as a '[p]roof of the effectiveness of the Bulgarian NGOs' advocacy at European level which led to international political pressure' (Ivanova and Bogdanov 2013: 09).

The Commission's intervention in Bulgaria demonstrates that even after accession, and in areas with weak or non-existing acquis like social care, it is possible for domestic NGOs, to mobilise external pressure, especially with supportive political and social factors. Crucial factor for NGOs' success was active lobbying at the EU level by European organisations and networks, some of which had members in Bulgaria. The context was also favourable – a shift towards a human rights approach to disability, beginning with the adoption of the UN Standard Rules and culminating in the UN Convention on the Rights of Persons with Disabilities (see Chapter 2), growing research evidence revealing inadequate care, abuses, and rights violations in institutions (Freyhoff et al. 2004), the BBC's 2007 documentary on Bulgaria's institutions, which shocked the international community. As one of the interviewees noted, 'there was enough in the background' (Interview ENGO2). Last but not least, the strong support for deinstitutionalisation from the cabinet of the Commissioner for Employment Social Affairs and Equal Opportunities, Vladimir Špidla[95] encouraged EC staff working on ESIFs to adopt a more proactive role. In the words of one of the interviewees, 'If the message comes from the top, we have to deliver' (Interview EC3).

The EC's intervention not only put direct pressure on the Bulgarian government to deinstitutionalise the care system but also ensured, at least formally, that NGOs are

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[95] Vladimir Špidla served as a Commissioner from November 2004 to February 2010

involved in the process (Interview EC3). This pressure led to the government regularly involving NGOs in working groups tasked with developing key strategic documents that guided the use of EU funds for deinstitutionalisation in Bulgaria. The Commission itself frequently met with NGOs, further reinforcing their role in shaping these policies.

Decreasing EU responsiveness to NGO demands

However, after reaching an agreement between the Bulgarian government and the EU on the use of European funds for deinstitutionalisation, the nature and degree of EU involvement changed. While the EC continued to monitor the process and participate in meetings and discussions, it was reluctant to intervene in the development and implementation of deinstitutionalisation projects.

The EU's withdrawal had a negative impact on NGOs' ability to influence the deinstitutionalisation process. Without the EC's mediation, government consultations with NGOs, when conducted, became formal exercises used only to legitimise the decision-making process and to fend-off NGOs' future criticism and calls for change (Shabani 2010). The proposed deinstitutionalisation projects focused more on closing large-scale institutions as soon as possible rather than supporting inclusion and participation in community.

Unable to influence planning and implementation of deinstitutionalisation, domestic NGOs, supported by European partners, continued to seek actions from Brussels through letters and meeting with officials (Interview NGO3). The Commission, however, abstained from intervening directly and only issued a general recommendation to the government to consult NGOs on key practical issues (Ivanova and Bogdanov 2013:

212).

The initiation of deinstitutionalisation for adult services in the second half of 2010s led to stronger mobilisation of human rights NGOs working in the area of disability. Domestic and European human rights organisations[96] joined forces, urging the EC to restrict investments in groups homes and prioritise alternative services supporting inclusion. They wrote letters and organised meetings with representatives of the EC (DG Regio and DG Employment), linking their demands to relevant EU legislation and policies in the area of human rights and ESIFs. Failing to convince the EC to intervene, they submitted a petition on the use of ESIFs for deinstitutionalisation in Bulgaria to the European Parliament's Petitions Committee (Panayotova 2018) and even initiated legal proceeding against the Commission (Case T-613/19), challenging its decision to continue funding the construction of new, albeit smaller, institutions. The support from European networks played a key role for enabling domestic organisations to use the opportunities for influence offered by the EU system, which required a lot of efforts, time, and resources (Salgado 2014). The Centre for Independent Living, a small organisation, whose capacity had been negatively affected by the withdrawal of foreign donors, could not have lobbied so intensively at the EU level without the help of its European partners. Other organisations, better resourced, also relied heavily on external support to reach Brussels (Interview NGO3).

Despite a favourable context, including strengthened ESIF provisions on deinstitutionalisation, increased media attention to group homes[97], and robust

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[96] The Centre for Independent Living – Sofia, the Bulgarian Helsinki Committee, the European Network on Independent Living (ENIL) and Validity foundation (former Mental Disability Advocacy Centre).

[97] Including a 2019 BBC documentary about group homes and an Al Jazeera reportage on the situation of small group homes. A critical report was also published by Disability Rights International (DRI 2020).

transactional activism (Petrova and Tarrow 2007), human rights NGOs were unable to mobilise pressure from Brussels and influence the planning and implementation of adult deinstitutionalisation.

The Commission's reluctance to intervene a second time can be attributed to several factors, both general and disability specific. For NGOs, prejudice towards disabled people and a lack of understanding among Commission staff about social inclusion and independent living principles were significant barriers. Many Commission staff did not perceive small group homes as segregating – 'They don't see anything wrong if the place looks nice, children are smiling, they are not tied to radiators!' (Interview ENGO1). Some desk officers and head of units[98] – key positions in managing ESIFs – 'do not understand how people with certain impairments might be able to live independently' (Interview ENGO2). An interviewed EC representative acknowledged that 'a discussion should be held within the Commission about what deinstitutionalisation is' (interview EC1).

The lack of political will at the EU level to address institutionalisation was another key factor, as emphasised by both NGOs and the Commission. While Commissioner Špidla, was dedicated to pushing for deinstitutionalisation through ESIFs, his successors were less committed (Interview EC3). 'What is needed now is a Commissioner who is committed. It [the push for deinstitutionalisation] needs to come from higher up, you can't leave it to the desks' (Interview ENGO1).

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[98] The ESIFs are managed by units within the relevant Directorate-Generals (e.g. DG Regio or DG Empl). Desk officers in these units deal with policy development and implementation issues.

A third factor is the EC's desire to showcase the deinstitutionalisation process in Bulgaria, where it was heavily involved, as a success. One ENGO representative noted that at a recent Brussels event, a Commission representative 'sounded like she was from the government – 'We have closed that many institutions, we have opened that many services…' (Interview ENGO1). Criticising the overreliance on small group homes or stopping related calls would mean questioning the success of its intervention, which the EC was understandably reluctant to do. Furthermore, the Bulgarian case had a much wider impact on EU and CEE countries' policies, leading to a policy framework on deinstitutionalisation at the EU level, with changes in ESIF regulations[99] described as 'ground-breaking' (Crowther et al. 2017:13) and even 'revolutionary' (Interview EC2). The EC takes pride in how the EU funds were used in Bulgaria for policy reform, with EC representatives referring to Bulgaria as 'the best example we have' (Interview EC3) and a 'pilot' (Interview EC2), which impacted the use of ESIFs for reforms in care systems across many countries in Central and Eastern Europe.

Finally, the involvement of traditional, state-friendly nationally representative organisations in the consultative process gave legitimacy to the policy outcomes and as discussed earlier, weakened the legitimacy of the demands of human rights organisations. In its response to the Petition submitted by human right organisations (2019, cited in Committee on Petitions 2019), the EC emphasised that representative

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[99] For example, a thematic objective was added concerning the transition from institutional to community-based services. Additionally, an ex-ante conditionality was introduced, requiring that the states where such a need was identified, which included Bulgaria and 11 other CEE countries, to include measures for the shift from institutional to community-based care. The EC's guidance on the ex-ante conditionalities for the ESIFs further states that 'building or renovating long-stay residential institutions is excluded, regardless of their size'. Moreover, it underlines that when judging whether a setting is a community-based service 'or simply a scaled down institution' the focus should be on whether it allows 'for independent living, inclusion in the community (including physical proximity of the location) and high-quality care' (European Commission 2014: n.p.).

organisations of disabled people are included in the monitoring committee of the operational programmes and can participate in defining the selection criteria for proposed operations and monitor the process.

Interestingly, none of the interviewed ENGOs and EC staff mentioned the changed political situation after accession, which previous studies have emphasised as a factor for the EU's unwillingness to intervene (Sudbery 2010). The EU had already significantly intervened in deinstitutionalisation policies; so the question became more about how much further the EU is willing to go.

The interviewed independent living advocates recognise the challenge of influencing the EC to take actions (interview ENGO 1). However, they also believe that genuine deinstitutionalisation and inclusion cannot succeed without support from Brussels due to the limited voting power of institutionalised disabled people (Interviews NGO1, NGO2, INGO1). It is only though strong domestic and/or international pressure that change can begin to occur.

Adverse effects of EC's engagement on NGOs policy influence

There is no doubt that the EU's intervention in Bulgaria helped place deinstitutionalisation on the government's agenda and start reforms, which over a period of ten years led to the closure of many traditional residential institution. The Commission's key role in this process has been recognised by all key stakeholders – government, NGOs, and EU institutions.

However, the EU's involvement also helped 'cement' the problematic approach to deinstitutionalisation, adopted by the Bulgarian government, which replaces large institutions with smaller ones, resulting in ‘re-institutionalisation’ (Mladenov and Petri 2020a). The measures proposed by the government and set out in various documents – National Strategic Reference Framework, Partnership Agreement, Operational Programmes – were legitimised by the Commission’s approval or these documents. Furthermore, the portrayal of Bulgaria as a good example of utilising EU funds for implementing transition from institutional to community-based services, has further strengthened the government’s position. As Noutcheva (2016:696) writes, ‘[e]xplicit declaratory support by Brussels for specific policies, even if symbolic in nature, confers external legitimization on particular interpretations of events, legislative acts, policy initiatives, etc.’ Several interviewed NGOs expressed frustration with the EC’s continual references to Bulgaria’s success, which focus on the closure of institutions rather than on how people are supported to live and participate in the community, a key challenge in many countries (Angelova-Mladenova 2019). This approach made possible the continuing proliferation of group homes. The framing of Bulgarian case as a success story also conceals numerous problems and controversial outcomes from the process, including the ongoing isolation of people placed in group homes, the institutional character of the settings, and abuse (Lumos 2015, Centre for Independent Living 2016). Eager to showcase deinstitutionalisation in Bulgaria as a success, the Commission has downplayed NGO reports of abuse in group homes, dismissing them as ‘isolated incidents’ (Interview ENGO1). Such statements, along with the uncritical promotion of Bulgaria’s success thus empowered the government to continue with its controversial policy, making it harder for critical human rights NGOs to influence a change.

Conclusion

This chapter explored how the ability and willingness of disability NGOs to influence disability policies have been affected by Bulgaria's accession and membership. It showed that changes in funding mechanisms associated with EU membership not only had a negative impact on the advocacy and campaigning capacity of most NGOs but also gave the state a strong leverage over them. Together with this, the selective and formal involvement of NGOs in policymaking did not allow them to significantly influence the principles underpinning disability policies, while at the same time increasing the legitimacy of these policies. Thus, EU funding and pressure shifted the balance of power towards the state, contributing to the preservation of the status quo in disability policies.

At the same time, critical NGOs were able to use the opportunities provided by the accession to initiate reform in the system of social care by mobilising external pressure. This was made possible by the European Structural and Investment Funds, which provided both the resources for large-scale reforms and a leverage for pressure. However, their policy influence was short-lived and decreased as soon as the EC stepped back, leaving the planning of the deinstitutionalisation process to the state. The policy reform, although generally in the spirit of human rights and social inclusion, failed to produce inclusive outcomes as people remain isolated in nicer, but still institutional settings. In this context, the continuing EU support for state-led reforms became a hindrance for NGOs' attempts to influence the outcomes.

Chapter 6: Conclusion

This research sought to analyse the role of the EU in the limited reforms of Bulgarian disability policies and practices towards independent living and social inclusion. While

Europeanisation has undoubtedly been a significant stimulus for reforms, it has not led to the type or degree of change anticipated**.** This lack of substantial change may not be surprising to scholars who point out the underdevelopment of EU social policy compared to other areas, question the potential of 'soft', non-compulsory EU policies to drive domestic change, or argue that the limited focus of social policy during accession has translated into weak policy influence. Indeed, the limits of Bulgaria's disability reforms might suggest that the EU did not have a significant impact on domestic policy. However, it could also indicate, as this research argues, that the EU might have, albeit unwittingly, contributed to preserving the status quo of paternalism and exclusion of disabled people, thereby reinforcing, rather than challenging, old views and practices.

The research explains the limits of disability support reforms in Bulgaria with the interplay between domestic and EU factors. It acknowledges that the EU has not been the sole external influence, with other major donors, the CRPD human rights discourses, neoliberal ideas, and economic crises also impacting on the country's disability policy. However, given the focus of this research on exploring the EU's role in Bulgaria's current disability policy situation, Europeanisation influences were the main subject of analysis. The research does not suggest that the EU is responsible for the re-institutionalisation of disabled people in Bulgaria or for the paternalism in the country's disability policies. Instead, it argues for a more nuanced understanding of the EU's influence which goes beyond the mere presence or absence of convergence.

The failure of disability policy reforms to adequately support disabled people's inclusion and independence was explored on the one hand, by examining a specific policy – assistance services. This involved analysing how the framing of the problem has affected the proposed solutions and how it has been affected by EU-promoted ideas. On the other hand, the research sought to understand the limited transformation by examining NGOs' willingness and ability to challenge and influence policies in the context of Bulgaria's EU accession and membership. The two sections discuss the findings and conclusions of the research in more details, focusing on policy content and the role of ideas, and on NGOs policy influence.

Disability policy and ideas

Using personal assistance as a case, the research identified three ways the limited change in disability policies has been influenced by the interplay of domestic and EU factors. The first concerns the interaction between two conflicting understanding of disability – the social model, and the still strong medical model in the county.

Although EU-promoted social inclusion has become a mainstream idea in Bulgaria, it has not replaced the medical perspective on disability. Instead, its impact has been mediated by the understanding of disability as a medical problem. This dynamic has resulted in measures and services aimed at social inclusion being underpinned by a traditional view of individual impairment as the primary cause for disabled people's challenges. This medicalised understanding has hindered the development of policies and measures that could support genuine inclusion in society. Thus, while the EU's active promotion of social inclusion and ESIF resources have fostered the development of new progressive services, such as personal assistance, these services have continued to reproduce paternalism and a passive role for disabled people. Similarly, the outcome of EU-driven deinstitutionalisation reforms has led to re-institutionalisation, albeit in smaller settings. Such policies and measures have failed to adequately support a real change in the lives of disabled people towards independent living and participation in the community. More importantly, they have become hindrances to such change, as framing certain measures and approaches as inclusive has made it more difficult, if not impossible, to challenge them from an inclusion perspective, as evidenced by the decades-long attempts of CIL – Sofia to reform the PA policy. Challenges from other perspectives, for-example, anti-austerity and income support, while successful in initiating reforms in personal assistance, have also failed to transform the service into a truly independent living one (Mladenov and Petri 2019).

The research provides insights into why the social inclusion perspective has not been able to challenge the existing medical perspective in Bulgaria. At the domestic level, the strong historical legacy has been a major hindrance to change – paternalistic attitudes towards disabled people are deeply rooted in the culture, and the medical model is institutionalised in practices such as the disability assessment, which forms the basis for all other disability policies. The “deep historical roots and wide institutional foundations” of welfare programmes make them more challenging to reform (Cox 2022:189). In addition, there has been a lack of political will for change due to the limited importance of disability issues as a policy area, vested interests, and corruption (Centre for Independent Living 2016). The specific constellation of NGOs is another key factor, which will be discussed in more detail in the next section. At EU-level, inconsistent understanding and engagement with social inclusion, conflicting recommendations (for example, spending cuts and improved social protection), and competing EU policy priorities have also hindered change.

The findings from this research resonate with recent studies on the implementation of disability rights in national contexts, which suggest that the diffusion of norms may result in the layering of old and new norms, ideas, and policies, rather than their replacement (Aucante and Baudot 2018). While the specific outcome of policy layering depends on the context, research has shown that it can be a major obstacle to change. For example, in the USA, the coexistence of conflicting paradigms – the social and medical model – has undermined the transformative potential of the main US disability rights legislation, the American with Disabilities Act (Burke and Barnes 2018). In France, adding disability rights to prevalent medical norms has had a paradoxical effect, reinforcing the legitimacy of old provisions and strengthening the position of the oldest stakeholders, while also transforming the scope of rights-based policies (Baudot 2018).

A second factor for the limited progress in independent living policies in Bulgaria is the interplay between the country's dominant medical model and the EU's economised social vision. This interplay contributed to the introduction of assistance programmes as an employment measure, subordinating disabled people's inclusion to assistants' employment. From the outset, providing subsidised employment or supporting family members to engage in employment on the open labour market has been a key priority of PA programmes. Even when issues related to disability support were addressed, they were frequently linked to economic goals. For example, deinstitutionalisation was discussed as a measure to ensure efficiency of social care services. This instrumentalisation of assistance services for achieving employment-related goals completely transformed their emancipatory potential, serving only to reinforce the passive and dependent roles traditionally associated with disabled people.

How have the EU and national factors interacted to influence the focus of the first PA programmes on assistant's employment, rather than on disabled people's inclusion?

The development of EU social policy, motivated by two competing but unequal agendas – the economic agenda and the social or human rights agenda from a disability perspective[100] shows the economic agenda as more powerful. Many scholars argue that EU social policy is subordinated to economic objectives or developed as an 'add-on' to the economic policy (Copeland and Daly 2015). This emphasis on economic development and employment put pressure on Bulgaria to address employment and economic issues with priority. This pressure was particularly strong during accession, characterised by unequal power relations between the EU and the candidates and strong EU leverage, stemming from the countries' desire to join the Union. Consequently, Bulgaria sought to reduce unemployment rates and benefit expenditures by modernising its welfare system and transforming benefits spendings into investments in employment. These goals could not be quickly and cheaply achieved by targeting disabled people, as this would have required much more comprehensive changes in institutions, policies, and practices, such as ensuring accessibility of infrastructure, transportation, information and communication, and making further investments. Therefore, the focus shifted to the employment of carers and potential assistants, rather than directly addressing the inclusion of disabled people.

Equally important for this outcome, however, has been the widespread medical perspective towards disabilities in the country, which saw disabled people as unable to work (to this day, the disability assessment is presented in a percentage of lost ability to work). This perspective prevented policymakers from viewing disabled people as

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[100] The research on European social policy distinguishes between 'social' and 'economic' terms. Here 'social' includes both the perspective of equality in terms of rights and the more social policy perspective of social protection (Scharpf 2002). However, the term 'human rights' more accurately captures the emphasis in disability studies on a rights- vs needs-based welfare approach to disability policy (Degener 2016b).

active participants in public life. It influenced the design of assistance services in a way that reduces disabled people to objects of care provided by assistants.

A few broader conclusions can be drawn about how the emphasis on economic development and employment, coupled with a weak and subordinate human rights perspective, influences the development of policies that reinforce disabled people’s exclusion. The imbalance between economic and social considerations can negatively affect the availability and access to support services in the community. For example, in the aftermath of the financial crisis, many countries sought to reduce public spending, leading to cuts in social services, more restrictive eligibility criteria for access to services, decreased quality of services, and a move back towards institutional type of care (Angelova-Mladenova 2019). The EU, viewing social spending as costs, strongly encouraged, even demanded, some member states to introduce such policies to reduce government deficits, even introducing a new microeconomic surveillance tool which sanctions for high deficit. However, disability support services, such as personal assistance, are essential for allowing disabled people to overcome social and environmental barriers and the reduced access to such support is an obstacle to their full participation in the community. Furthermore, limited availability of community services forces many disabled people who lack adequate support at home to ‘choose’ institutional care.

The prioritisation of employment could also lead to disability services being provided as an element of workfare conditionality, where engagement in employment is a condition, or at least an advantage, for accessing services. Such an approach would not only restrict access of many disabled people to support but could also lead to the devaluation of those disabled people who may be unable to work or find work.

The pressure to boost employment among disabled people, as part of efforts to enhance productivity and stimulate economic growth, can also lead to the prioritisation of sheltered employment options. This is often seen as a more straight-forward and cheaper alternative to initiatives that promote inclusion in mainstream employment. Without broader measures, however, disabled people will not have an adequate an equal choice of employment options. The dominance of sheltered employment options will only sustain segregation.

A third aspect illustrating how the interplay between domestic and EU factors has contributed to the unchanged situation in independent living in Bulgaria concerns the interaction between the EU's policy on aging and the country's entrenched medical perspective on disability. The framing of old age as a political problem for the EU has led to an increase in policies on aging with a focus on health and care (e.g., long-term care, healthy aging). Disabled people have also been targeted by these policies which link disability, similarly to frailty, with the need of long-term care (European Commission 2021b). This has created a growing tension in the EU's approach to disability, as captured by the Statement of the European Network on Independent Living (2022) on the 2022 EU Care Strategy: "The Care Strategy contains no call on the member states to fully implement the UNCRPD… The document addresses disabled people solely as needing "care"'. This tension has weakened the influence of the rights-based perspective and has reinforced the already dominant medical model in Bulgaria. In addition, the traditional approach in Bulgaria of treating older and disabled people as one group with similar support needs, addressed through similar segregating measures (institutional care), has further facilitated the adoption of a care-based perspective towards disabilities.

NGOs willingness and ability to challenge policies

The status quo of disability policies in Bulgaria has also been sustained by the dominance of organisations with traditional views, recognised as nationally representative organisations of and for disabled people, based solely on the size of their membership or clientele. These organisations favour medical model policies and practices inherited from state socialism and oppose attempts for more radical changes, such as the introduction of personal assistance law. They enjoy good, even friendly, relationships with the government, institutionalised access to policymaking as members of the National Council for Integration of People with Disabilities, and financial sustainability, ensured with the help of annual state subsidies. At the same time, human rights organisations which actively challenge traditional policies and advocate for radical reforms, are fewer and weaker, finding it difficult to oppose the dominant agenda. The strong power imbalance in the sector was best summarised by one of the interviewees (who did not belong to either group of organisations) – ‘there are the nationally representative organisation and vsya ostalnaya svoloch (from Russian – *вся остальная сволочь*, meaning ‘the rest of the scum’).

The discussion of the impact of accession on NGOs’ willingness and ability to influence policy should therefore distinguish between the effects on traditional, nationally representative disability organisations and on human rights organisations. The study argues that the changes accompanying Bulgaria’s EU accession and membership have paradoxically reinforced the power imbalance in the disability sector by weakening human rights, reform-oriented organisations, and strengthening traditional, state-friendly organisations. The next part will examine how changes in the EU funding mechanism and the emphasis on NGO-state partnership have contributed to this situation.

The role of funding and the emphasis on partnership

The research has confirmed the observations of previous studies of the limited and decreasing financial viability of NGOs, especially following the withdrawal of foreign donor funding which has been key to the growth and development of the sector. This has had a strong negative impact on human rights advocacy NGOs, for whom external donors have traditionally been a key source of support[101]. Their decreasing organisational capacity has not only made them less able to follow policies and engage in advocacy activities directly, but it has also hindered their ability to mobilise grassroots and community support as well as to influence attitudes by raising awareness about disability rights and the social understanding of disabilities. The nationally representative organisations, however, having access to stable government funding, have been largely unaffected by the reduced funding opportunities.

Contrary to the expectations, the access to EU funds has not contributed to the revival of human rights NGOs and the strengthening of advocacy. The control over EU funds in the context of declining foreign funding opportunities has allowed the state to influence and shape NGOs' priorities[102]. The state-managed EU funds have been

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[101] Organisations providing services, have been able to secure state funding or mobilise private funding.

[102] Thus, some of the key challenges faced during the pre-accession period, such as NGO dependency on foreign funding, financial instability due to short-term project funding, and the inability to determine their own agendas,

directed exclusively towards service provision, leaving limited opportunities for engagement in advocacy. This has contributed to the transformation of many NGOs into service providers, focused on ensuring the sustainability or improving their services, rather than on questioning or challenging the status quo. Many human rights advocacy organisations have also been pushed towards service provision. This transformation into service providers and their withdrawal from advocacy have meant that critical human rights organisations have been less able to engage in transactional activism at the domestic level. At the same time, nationally representative organisations of and for disabled people had privileged access to ESIF funding, with certain calls designated only for them, while all other disability NGOs had to compete among themselves for funding.

The promotion of NGO-state partnership by the EU has also strengthened the position of traditional disability organisations, while critical human rights organisations have found it difficult to gain access to policymaking. Traditional organisations have benefited from the early institutionalisation of the National Council for Integration of People with Disabilities, of which they became members. Described as a ‘marriage of convenience’ by one of the interviewees (Interview NGO1), the NCIPD granted access to policymaking to organisations with traditional views, not likely to demand radical change, while excluding critical human rights organisations. The financial incentives (annual subsidies) and the political incentive (participation in NCIPD) have further made nationally representative organisations reluctant to criticise or challenge state policies.

In addition, the EU’s emphasis on partnership with non-state actors has increased the

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have persisted after accession. However, the significant change is that the state, rather than external donors, is now at the steering wheel.

legitimacy of NCIPD and traditional organisations, while the legitimacy of human rights NGOs and their ability to challenge state policies suffered. This process was facilitated by the narrow definition of representativeness based on numbers, which favoured service providers and organisations with large membership.

Effective mobilisation of external pressure?

Together with empowering traditional organisations, EU accession also contributed to strengthening critical NGOs by providing access to a new, supranational level for exerting pressure. Faced with an unfavourable domestic context, critical domestic organisations actively sought to use the opportunities provided by the structural changes associated with EU accession to mobilise external pressure. Contrary to expectations for weakening of this mechanism after accession, NGOs successfully applied external pressure on the state to initiate deinstitutionalisation reforms, the need from which had been rejected by the NCIPD a few years earlier. Engagement with, and support from, European networks were crucial for this positive outcome of the campaign, which was as much European as it was domestic. Another crucial factor was the focus on the ESIFs, which has provided more opportunities for EU to intervene even in areas with weaker competence.

However, the effect of external pressure on strengthening NGOs was limited in time. With the decreasing EU pressure, the involvement and ability of NGOs to influence reforms waned, impacting the outcome. The reform failed to contribute to the inclusion of disabled children and adults, as the new support services, which replaced traditional institutions, reproduced old practices and approaches. Moreover, the EU’s praise of the reform and its unwillingness to respond to NGOs' demands further legitimised the outcomes and the process, weakening human rights NGOs' demands for change.

Evolution of EU influence and NGO involvement in policymaking

The research covered the period from the mid-1990s, when the first disability-specific law establishing the NCIPD was adopted and rapid growth of NGOs began, until the end of 2019 when the field research was completed. The end of 2019 also marked the adoption of a PA law. This extended period allowed to observe how EU influence and NGO involvement evolved.

The finding suggests that EU ideational influence on Bulgarian disability policies continued throughout the period. The country's EU accession and changes in policy instruments at the EU level (e.g., the adoption of a disability strategy and the introduction of the European Semester) did not significantly alert the type or strength of ideational influence, at least in the area of disability support, which was the research focus. Importantly, throughout the period, broader ideas about the role of social policy and concepts from close and intersecting policy areas (for example, aging and care) had as much influence as disability-specific ideas.

The main changes concerning the EU's influence were associated with the transition from pre-accession funds to ESIFs. This transition gave the country access to large amounts of EU money to support developments in various areas, including social policy, leading to reforms in disability support – key disability policies were implemented with co-funding from ESIFs. The specific management arrangements for ESIFs allowed the government more control over how the money was spent and who gets funded, compared to pre-accession arrangements. At the same time, the ESIFs opened opportunities for stronger and more direct EC influence on domestic policies after accession, when EU leverage is generally more limited. EU pressure and requirement concerning the use of the ESIFs were key to initiating the deinstitutionalisation reform in the country.

With regard to disability NGOs' involvement in policymaking, the findings suggest that the situation has more or less stagnated, even worsen for human rights organisations, which find it more difficult to secure funding for advocacy. The NCIPD, created in 1995 and dominated by traditional organisations and service providers, remains the main consultative body in the area of disabilities. The ESIFs' emphasis on partnership led to the establishment of new consultative bodies with NGO participation. However, this development was both reluctant and delayed, and the bodies were only concerned with the use of the ESIFs. This did not result in increased opportunities for policy influence for disability organisations, apart from those within the NCIPD. The NGOs' passion for advocacy, which was visible in the second half of the 1990s and the beginning of the 2000s, enabled by foreign donors' funding, has gradually given way to engagement in service provision and a withdrawal from political activities.

Over the past few decades, an interesting trend has emerged: children's organisations, united in a national network, have become stronger and more involved in disability advocacy. Their focus, however, has been primarily on children with disabilities and their care, rather than on promoting independent living. Their advocacy approach has been significantly influenced by their involvement in service provision. Towards the end of the 2010s, a parents' group, mostly involving mothers, also became more visible, mirroring similar developments in other CEE countries (Mladenov and Petri 2019). The group managed to mobilise public support that led to the adoption of a PA law. However, internal conflicts led to the split of the group, which negatively affected its public image and advocacy effectiveness. While these recent developments were not explored in this research because they occurred outside its timeframe, they offer a valuable topic for further exploration.

Relevance of the findings

This research underscores the importance of domestic context in mediating the influences of Europeanisation. When interacting with country-level factors, the transformative power of the EU can lead to pathological outcomes, reinforcing rather than changing the status quo. The sectoral focus, in particular, highlights the role of ideas at both the domestic and EU level, as well as the constellation of NGOs.

What is the relevance of these findings and conclusions for other countries in the region and beyond? Bulgaria represents a specific case, in its transition from state socialism to democracy and market economy and in its process of joining the EU. Its EU accession was slower and more challenging compared to most CEE countries. However, available research suggests that the country is a typical case when it comes to disability policy development. The challenges it faces in developing independent living and social inclusion policies are common to many countries in the region, as is the dominance of big traditional organisations with roots in the state-socialist era. Therefore, the insights from this research are relevant for other countries in the region. Further comparative research could provide a more nuanced picture of the similarities and differences between these countries. It would also enhance understanding of the factors affecting the failure of disability reforms and how Europeanisation influences interact with the domestic context.

The significance of the findings extends beyond the CEE region. With the global shift towards disability rights in the last decades, many countries, including pioneers in the rights paradigm, such as the USA, face challenges in integrating the rights paradigm with their existing welfare policies. Consequently, the insights gained about the role and the diffusion of ideas have wider relevance.

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Appendix 1: List of interviews

Code/number	**Organisation**	**Date**
ENGO1	European NGO in the area of disability	December 2019
ENGO2	European NGO in the area of disability	December 2019
NGO1	Advocacy organisation	December 2019
NGO2	NGO providing services	December 2019
NGO3	Advocacy organisation	December 2019
NGO4	NGO providing services	December 2019
NGO5	Nationally representative organisation of/for disabled people	January 2020
NGO6	Organisation engaged in service provision and advocacy	January 2020
NGO7	Advocacy organisation	January 2020
EC1	DG REGIO	January 2020
EC2	DG EMPL	January 2020
EC3	DG EMPL	January 2020
CS1	Former expert in the Child Protection Agency	May 2021